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THE PROCESS USED BY SURROGATE DECISION-MAKERS TO WITHHOLD AND WITHDRAW LIFE-SUSTAINING MEASURES IN A CATHOLIC INTENSIVE CARE ENVIRONMENT

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by

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DEDICATION

The surrogates who came forward to participate in this study allowed me to glimpse one of the most intimate experiences of the human condition; the death of a loved one. I was often humbled by the surrogates' frank willingness to share time and tears with me so that others may profit and learn from their experience. I am deeply indebted to each of them for helping me to understand. I dedicate this work to the surrogates, their families and to those for whom they made such a loving, yet difficult decision. I hope you can take some comfort in knowing that you had the courage and conviction to learn, understand, and decide.

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One of the people in this world whose opinion I value a great deal, once told me that to complete a dissertation would irrevocably change who you are. How true these prophetic words turned out to be. I am a changed person, and I hope one for the better.

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THE PROCESS USED BY SURROGATE DECISION-MAKERS TO WITHHOLD AND WITHDRAW LIFE-SUSTAINING MEASURES IN A CATHOLIC INTENSIVE CARE ENVIRONMENT

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Both families and health care providers struggle with the decisions regarding the amount and type of care that can be given to the terminally ill. Families most often become the surrogate for a loved one, whether the family member desires to do so or is prepared to do so. While this study was not designed to produce a how-to handbook, it does give some idea about the surrogate's decision-making process. The purpose of this grounded theory, qualitative study was to generate a theory about the process used by surrogate decision-makers who have decided to withhold or withdraw life-sustaining measures from those for whom they act as medical decision-makers within a Catholic intensive care environment.

The study was conducted with 17 surrogates of terminally ill persons who received care in an intensive care environment prior to the patient's death. The

participants in this study were recruited with the assistance of a local health care network's nursing staff. Through direct mailings, surrogates of patients who died in the hospital were mailed invitation letters by the hospital staff.

Stories obtained from the surrogates through face-to-face interviews were analyzed and through constant comparison of the data, nine themes emerged. These themes were then clustered into areas or domains representing the decision-making process. The nine themes within their respective domains include: (1) Personal Domain: rallying family support, evaluating the patient's past and present condition and preferences, viewing the past and future quality of life for the patient, (2) Intensive Care Environment Domain: chasing doctors, expressions of the relationship with the health care team, the health care team confirms the probable medical outcome of continued treatment, and (3) Decision Domain: arriving at a new belief, getting alone to make the decision, and communicating the decision to withhold and withdraw life-sustaining measures. The themes and domains are expressed as a theory with an accompanying model.

The study results have demonstrated opportunities for health care providers to improve education and change practice when trying to understand and support surrogates. Additional opportunities were found for further research to expand nursing knowledge related to the broader rubric encompassed by end-of-life issues.

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CHAPTER 1

INTRODUCTION

Advances in modern medical science have simultaneously created a burden and a benefit for many people in the United States. We benefit from longer, more productive lives mostly free of infectious diseases, only to die from chronic ailments such as cardiac illnesses and cancer. At the end of our lives, we endure the burden of prolonged and frequent admissions to acute care hospital facilities and intensive care environments (Field & Cassel, 1997). As a result of tension between burden and benefit, we are beginning to try to understand dying in the United States and those who must make crucial decisions about end-of-life issues.

Up to 86% of decisions regarding life-sustaining measures are negotiated in some way by someone other than the dying patient while the dying patient is in an intensive care environment within a hospital setting (Swigart, Lidz, Butterworth, & Arnold, 1996). It is often the family members who become the surrogate decision-makers, regardless of whether they desire to do so or understand the patient's wishes in regard to the withholding or withdrawing of life-sustaining measures. The surrogate's position is often complicated in that only 15% of hospitalized patients execute some form of advance directive delineating their desires related either to advanced care during times of critical illness or when futility of continued treatment may become a reality (Swigart et al., 1996). Most of those advance directives, however, do not give clear direction to the surrogate or health care team to cover all situations under which the directive may be enacted (Gilbert, Counsell, Guin, O'Neill, & Briggs, 2001). This uncertainty can lead to a

period of paralyzing indecision for the surrogate before she or he can accomplish the job of deciding for another (Hiltunen, Medich, Chase, Peterson, & Forrow, 1999). Additionally, the ambiguity surrounding many advance directives can leave a considerable number of situations in which surrogates must try to understand if they are making the appropriate choice for their loved ones (Johnson, Cook, Giacomini, & Willms, 2000). One report showed that 24% of families with loved ones in intensive care were in "decisional conflict" (Hiltunen et al., 1999), meaning that one quarter of the surrogate population did not know what their family members wanted in regard to the withholding or withdrawing of life-sustaining measures in intensive care situations.

Modern medical science has an increasing ability to sustain life in terms of maintaining beating hearts and oxygenated blood streams, even in cases in which individuals may never again become aware of their surroundings (Burrows, 1994). The situations in which this purely biological state of life can be maintained will most certainly continue to demonstrate an upward trend. At issue, then, will be the dilemma of whether to conceptualize the end of life in terms of prolongation of vital functions, irrespective of mental status and how to negotiate end-of-life dilemmas in an era in which prolongation of a beating heart does not necessarily imply functional or mental capacities.

Projections show that the percentage of people over 65 in this country will continue to increase. For the census year 2000, the United States showed slightly more than 14% of its citizens to be over age 65, and the projected totals for the year 2030 rise to 21% (Centers for Disease Control and Prevention's National Center for Health

Statistics, 2003; Federal Interagency Forum on Aging-Related Statistics, 2003). These older persons are the highest users of health care dollars in the country (Federal Interagency Forum on Aging-Related Statistics, 2003). The inference can be made, then, that this section of the population will consume an ever-increasing portion of the total American health care dollar.

People over 65 are also more likely to experience death from chronic debilitating diseases (Centers for Disease Control and Prevention's National Center for Health Statistics, 2003; Federal Interagency Forum on Aging-Related Statistics , 2003), and they most often die in an intensive care environment (Field & Cassel, 1997; Swigart et al., 1996). Therefore, it can be inferred that an increasing amount of the total American health care dollar will pay for invasive interventions for people who, at the end of their lives, may not desire to receive them.

The cost and the increasingly widespread availability of life-sustaining medical interventions must be examined in the interest of improving care for all those who reach the age where chronic and life-threatening illnesses may become more prevalent. The need for sustained inquiry, however, becomes especially critical where issues involving surrogacy for the dying become a reality. The stresses upon those responsible to the recipients of care, such as surrogates, and to the health care system in general warrant discussion. Both young and old will, at some point in their lives, most certainly be faced with the need to understand the issues surrounding decisions to withhold or withdraw life-sustaining measures.

STUDY PURPOSE AND DEFINITIONS

Professional organizations, such as the American Nurses Association (ANA), have adopted position papers, codes of ethics, and policies regarding the withholding and withdrawing of life-sustaining measures (American Nurses Association, 1985). The most recent revision of the ANA's Social Policy Statement includes a specific call to the profession of nursing to "partner with individuals, families, and populations to address issues such as …emotions related to experiences of birth, growth and development, health illness, disease and death" (American Nurses Association, 2003). The ANA has recognized that nursing has a specific role in the care of the dying patient. Nurses must collaborate with individuals who engage in decisions regarding the withholding and withdrawing of life-sustaining measures in intensive care environments.

Although there is considerable discourse regarding end-of-life care in the scientific and lay literature, there is little written about the process of decision making used by surrogates who have engaged in the process of withholding and withdrawing life-sustaining measures. Most medical personnel place a significant emphasis upon the scientific phenomena surrounding the dying process, but theirs is only one of many perspectives deserving consideration. Research should also include other competing influences that may affect the withholding and withdrawing of life-sustaining measures. Other influences should include the views of the surrogates who often make decisions for those in intensive care environments.

Another one of those competing influences may be the religious atmosphere of the hospital environment. Institutions managed by religiously affiliated bodies have not

been examined in relationship to end-of-life issues, potentially because there are far too many different faith-based traditions from which to choose to explore this aspect fully. World religious preferences include over 2billion Christian-based, and of those, over 1 billion are Catholic (Barrett, Kurian, & Johnson, 2001). Narrowing the field of study to those institutions influenced by Christian theology seems reasonable, as the United States' prevalent religious preference over 80% Christian-based, including over 30% Catholic (Levinson, 1996).

The Catholic Church has taken a leadership role in the structuring of guidelines for Catholic-managed health care institutions. For instance, the United States Conference of Catholic Bishops recently issued a new edition of guidelines for Catholic institutions, titled Ethical and Religious Directives for Catholic Health Care Services (United States Conference of Catholic Bishops, 2001). The Catholic Church's influence upon the operations of a hospital setting may demonstrate the impact faith-based considerations have on decisions to withhold or withdraw life-sustaining measures.

Other competing influences related to end-of-life decisions must also be considered. For example, there is no consensus about a definition of the phrase "withholding and withdrawing of life-sustaining measures." In part, this may be due to the competing personal opinions and values associated with these terms, which are rooted in the individual perspectives of the patient, the surrogate, and the health care providers. This lack of understanding surrounding the withholding and withdrawing of life-sustaining measures leads to confusion and deep division among the professional, lay, ethical, governmental, and religious bodies with interests in these issues.

Hence, the purpose of the proposed study was to generate a theory about the process used by surrogate decision-makers who have decided to withhold or withdraw life-sustaining measures from those for whom they act as medical decision-makers within a Catholic intensive care environment. This gives rise to the need for consistent definitions of various terms to be employed in the study.

Definitions

Surrogate

For the purposes of this study, a surrogate was defined as only those persons who are 21 years of age or older and who are legally designated as medical decision-makers for other individuals who are incompetent to make their own decisions. The terms *surrogate* and *guardian* may be used interchangeably.

Life-sustaining measures

Life-sustaining measures incorporated medical technological equipment, procedures, devices, processes, modalities and other interventions that are known by medical science to be life-sustaining or prolonging. These included but were not limited to artificial ventilation, artificial hydration and the devices necessary to deliver it, artificial nutrition and the devices necessary to deliver it, medications to control heart rate or blood pressure, blood and blood products, cardiopulmonary resuscitation, surgical interventions, hemodialysis, chemotherapeutic agents, and other medical interventions deemed by a health care team to be life-sustaining or prolonging.

Withholding and Withdrawing of Life-sustaining Measures

Withholding of life-sustaining measures was defined as the purposeful act of refusing consent for life-sustaining measures. Withdrawing of life-sustaining measures included the purposeful act of removal of life-sustaining measures.

Intensive Care Environment

An intensive care environment was defined as

> A specially staffed, specialty equipped, separate section of a hospital dedicated to the observation, care, and treatment of patients with life threatening illnesses, injuries, or complications from which recovery is possible. It provides special expertise and facilities for the support of vital function and utilizes the skill of medical nursing and other staff experienced in the management of these problems. (Bajan, 2003, ¶ 5)

This definition was applied to areas, units, or environments of hospitals, such as conventionally named intensive care units, as well as other expressly designated sections of a hospital denoting specialized care, such as step-down or intermediate care units.

Catholic Intensive Care Environment

A Catholic intensive care environment was defined as an intensive care environment (previously defined), which is influenced in policy, practice, or both by the most recent edition of the Ethical and Religious Directives for Catholic Health Care Services. (United States Conference of Catholic Bishops, 2001).

BACKGROUND

Considerable discourse has taken place over approximately the last 50 years concerning issues of withholding and withdrawing life-sustaining measures. The various competing voices that comprise those most concerned with the issues of withholding and withdrawing life-sustaining measures make a single voice difficult if not impossible to hear clearly.

Historical Perspective

The history of surrogate decision making has been developed as a result of landmark cases involving persons placed in situations in which they were no longer able to participate in their own health care decisions. The first of these seminal cases involved a young woman named Karen Ann Quinlan. Following an auto accident in 1975, Quinlan was placed on a ventilator, and artificial feeding tubes were used to maintain her in a coma. The ventilator and artificial feeling tubes preserved Quinlan's life for months, and eventually her condition deteriorated to a persistent vegetative state. The family enlisted the guidance of their parish priest and consulted with the diocesan leadership regarding the Catholic Church's teachings in order to arrive at their decision to request the removal of life-sustaining measures for Quinlan.

Following many lower courts' decisions, Quinlan's parents were heard by the New Jersey Supreme Court and, based upon the Constitutional right to privacy, they were allowed the removal of life-sustaining technologies. While much controversy surrounded the landmark decision giving Quinlan's parents the right to remove life-prolonging technologies, their withdrawal of treatment did not, in fact, result in Karen Ann Quinlan's

death. Instead, Quinlan lived for an additional 10 years in a nursing home. Some believe that this very public display of the struggle endured by all involved in the Quinlan case gave birth to the right-to-die movement in the United States (Schwarz, 1999; Edge & Groves, 1999; Pence, 2000).

A second influential case is that of Nancy Cruzan. The survivor of an automobile accident in 1983, Cruzan was sustained in a persistent vegetative state with artificial nutrition and hydration for seven years. Like the Quinlan case, Cruzan's family eventually decided to withdraw life-sustaining measures and requested hearings by numerous courts in order to do so. This family also enlisted the help of the Catholic leadership, as was demonstrated by the United States Catholic Conference, which filed an amicus brief in support of Nancy's parents and their decision to discontinue life-sustaining measures. Other briefs of amici curia*e* were filed both in support of and against the family's position (*Cruzan v. Director*, 1990).

In 1989, the United States Supreme Court heard the Cruzan case and issued an opinion that contradicted the family's belief that Nancy would not want to be kept alive by artificial means. The Court's decision hinged upon the fact that Nancy was incompetent to make her own health care decisions, and clear and convincing evidence was not sufficiently present to honor the family's desire. Three of Cruzan's friends came forward at a later date and provided testimony that supported the family's opinion that Nancy would not want to be maintained in a persistent vegetative state, and in 1990 the Missouri State Supreme Court issued a ruling that held no objection to the removal of

Nancy's feeding tube (Edge & Groves, 1999; Pence, 2000). Her feeding tube was removed, and she died in late 1990.

These women's cases have come to represent determining events on the historical timeline of health care. As with all groundbreaking legal decisions, the interpretations and applications of the meanings of the decisions continue to evolve over time. Cultural context shapes the understanding, application, and meanings behind many decisions of a legal nature (Flynn, 2000). Since the time of Karen Ann Quinlan and Nancy Cruzan, this evolution can be seen in the proliferation of state and federal legislation focused on issues related to death and dying (Gelling, 1999; Shelstad, 1999).

To avoid future situations in which states would be faced with other cases similar to Cruzan's or Quinlan's, Congress passed the Patient Self Determination Act (PSDA) as part of the Omnibus Budget Reconciliation Act of 1990. The PSDA protects the rights of an individual who becomes incompetent to make his or her own health care decisions and allows for the anticipatory selection of a person of choice to speak on his or her behalf should he or she become incapable of communicating. The PSDA requires all health care facilities receiving federal funding in the form of Medicare or Medicaid money to provide patients with a written statement concerning their rights related to the acceptance and/or refusal of treatment. Additionally, health care institutions are called upon to educate the public concerning advance directives (Shapiro & Bowles, 2002) and to provide information regarding individual state laws as they relate to advance directives (Maxfield, Pohl, & Colling, 2003).

Many initiatives to avoid cases such as Nancy Cruzan's and Karen Ann Quinlan's have come to fruition. Laws have been enacted to safeguard the rights of the terminally ill and dying at both the federal and state levels; however, bitter differences of opinion continue to plague all parties concerned with this emotionally charged issue.

The historic Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) (Connors et al., 1995) was conducted in order to understand and describe the experiences of critically ill patients prior to death. It was hoped the SUPPORT study would explain and describe the difficult experience some patients (and their loved ones) endured at the end of life in a context in which doctors were thought to be too aggressive in their pursuit of life-sustaining measures. The major intervention of the study was the development of nursing staff who were specifically trained in skills to assist families and physicians to communicate and to collaborate about treatments at the end of life (Hiltunen et al., 1999).

When originally published, the intervention of nurses to facilitate communication showed a considerable lack of effectiveness in improving collaboration about end-of-life issues among patients, families, and physicians. Using the SUPPORT nurses' study documentation in the form of logs and dairies, a secondary analysis was conducted of the SUPPORT study. This secondary analysis found nurses had impressions of consistent themes in the decision-making processes families underwent, and the analysis underscored the complex nature and overwhelming responsibility associated with the act of coming to these determinations (Hiltunen et al., 1999). Furthermore, analysis of the nurses' logs and narratives, used as documentation tools during SUPPORT, revealed

similar themes in the issues families considered when making choices regarding the end of life. One example of the themes was patients' and families' willingness to acknowledge the terminal nature of diagnoses. Another of numerous themes was the barriers to effective communication among and between those responsible for decision making (Murphy, Price, Stevens, Lynn, & Kathryn, 2001).

Information obtained from sources such as SUPPORT's secondary analysis has brought to light the complexities surrounding end-of-life decisions. This may be one of the reasons why many states have enacted legal protections for the families, patients, and care providers involved in end-of-life decision making. The most publicized of these protective experiments is unfolding in Oregon. In 1994, Oregon passed the Death with Dignity Act, in which a dying person has the legal right to seek help in dying from a physician. After multiple requests by the patient, the patient's physician is allowed to prescribe a lethal overdose of medication. The Death with Dignity Act was legally challenged in various courts in Oregon until October 1997, when it became an enacted law after the United States Supreme Court refused to hear a case that could have made the act unconstitutional (Oregon Department of Human Services, n.d.).

The constitutionality of laws like Oregon's Death with Dignity Act has yet to be fully tested in the court system, and the morality of such laws has yet to be determined by the court of public opinion. However, United States Attorney General John Ashcroft brought suit against the State of Oregon and the Death with Dignity Act. "[Ashcroft declared] that assisting suicide is not a legitimate medical purpose under the Controlled Substances Act" (Wiley, 2002, p. 459). It remains to be seen whether or not the statute

will remain in place over the long term as Ashcroft's successor, Attorney General Alberto Gonzalez, continues with the fight against Oregon's legislation.

Even in the presence of federally guaranteed rights under the terms of the PSDA, Americans continue to wrestle with the question of whether to withhold or withdraw life-sustaining measures. In the most recent debate regarding the right to die, Terri Schiavo, a woman in Florida, collapsed in her home, presumably from a potassium imbalance. This 1990 incident resulted in cardiac arrest and an anoxic brain injury. Currently, Schiavo is presumptively diagnosed as in a persistent vegetative state. Her husband has been attempting to pursue the legal removal of her feeding tube through the courts since 1992 and has been in bitter disagreement with Schiavo's parents over the withdrawal of life support since 1993. Their battle as a family continues to rage on in the public arena 10 years later.

Such public involvement recently prompted the Governor of Florida to intervene and hastily pass legislation to limit feeding tube removals for persons who are in a persistent vegetative state (World Federation of Right to Die Societies, 2003; Brody, 1988). The question of legality of Florida's amended law refusing the rights previously given by the PSDA and its implications for the wider American culture continues in and out of the courts. The Florida Supreme Court decided to strike down the legislation on the grounds that it overstepped the bounds of the governor's branch of government in private medical issues (Silverman, 2005). At the time of this writing, the controversy continues to be debated and has generated significant discourse, particularly on the Internet and in

the popular media. For the 21st Century, this case will clearly be analogous to the Cruzan and Quinlan cases of the 20th Century.

The Catholic Church's Influence

Like Terri Schiavo, other individuals have been kept alive in persistent vegetative states for many years. However, the influence of the Catholic Church has had considerable general and case-specific involvement in many past and more current issues involving withholding and withdrawing of life-sustaining measures. For instance, the Karen Ann Quinlan case gave society a rare glimpse into the personal pain experienced by some Catholics who wrestle with such decisions. Quinlan and her family were devout Catholics, and throughout the ordeal leading to the termination of Karen Ann's life-sustaining measures, the Quinlan family regularly consulted with the Catholic leadership of the local diocese. From that point forward, Catholic laypeople have been eager to have their faith beliefs registered in legal decisions regarding life-sustaining measures. Many Catholics have been adamant in their desire for the courts to support their rights to express their faith in a way that was consistent with Catholic beliefs regarding the end of life.

The Catholic Church has struggled with end-of-life issues long before Karen Ann Quinlan. Many events took place to bring the Catholic Church to its present position regarding end-of-life care. As early as the 16th Century, Francisco De Vitoria, a Spanish Dominican theologian, reviewed the question of whether an individual was obligated to prolong life by eating certain foods or using medicines if she or he should become sick. Vitoria concluded that a person was not under an obligation to endure expense or pain for

the sake of prolonging life, particularly in the face of uncertain outcomes (Panicola, 2001).

Another Spanish Dominican from the same period, Domingo Bañez, introduced the terms *ordinary* and *extraordinary* into the dialogue concerning the treatments that a devout Catholic must undertake to preserve life. These concepts remained somewhat ambiguous until the 17th Century, when John Cardinal DeLugo clarified these two terms. DeLugo felt that devout persons were absolutely not required to use extraordinary means to sustain life when there was "no reasonable hope of benefit" (Panicola, 2001).

The 18th Century saint Alphonsus Liguori espoused the idea that a certain amount of subjectivity lay with the interpretation of what means should be used to extend life (Panicola, 2001). Most of the Church's theologians interpreted the use of ordinary means as always required of someone to preserve life. Extraordinary means, however, were not required of the faithful. This interpretation of life-sustaining measures remained relatively unchanged until the writings of the 20th Century Jesuit theologian Gerald Kelly.

Kelly, an American priest, wrote a seminal article in 1950 regarding the interpretation of ordinary and extraordinary as applied to life-sustaining measures, and the Catholic moral stance regarding one's responsibility to prolong life. Kelly echoed the teaching of the moral theologians who came before him but added one important idea. While reaffirming the notion that ordinary and extraordinary means are the moral yardstick used to measure means to preserve life, Kelly introduced the idea that the burden of any given ordinary or extraordinary means may outweigh the benefit that one

may receive from it. Kelly's article shook the theological foundation of the Church by questioning whether or not a faithful Catholic is always required to use even ordinary means to preserve or prolong life (Panicola, 2001).

So profoundly influential was Kelly's article that Pope Pius XII used Kelly's thoughts to address the International Congress of Anesthesiologists in 1957. Pope Pius made reference to St. Thomas Aquinas' argument that mortal life is not the ultimate end of human experience. Rather, according to the Pope, when a person no longer has the ability to obtain spiritual gifts, as in one's ability to have an individual relationship with God, treatments to prolong life become obviated in light of the sacred Biblical promise that humans should proceed to a better spiritual place (Panicola, 2001).

Kelly's and Pope Pius' words were to shape the doctrine of the Church for many years to come. The Congregation for the Doctrine of the Faith, founded in 1542, has been given the monumental task of advancing and maintaining the moral stance of the Catholic Church throughout the world. This body disseminated the Church's stance on euthanasia in 1980 and also introduced new terminology to be used when morally measuring life-sustaining interventions. The Declaration of Euthanasia introduced, for example, the terms *proportionate* and *disproportionate* to ascertain the direction one should choose in regard to the use of medical resources to prolong or preserve life (Panicola, 2001).

In the early 1980s the Church attempted to obtain consensus in regard to life-sustaining measures and, in particular, those related to artificial hydration and artificial nutrition. The New Jersey Catholic Conference, the Texas Catholic bishops, the Committee for Pro-Life Activities of the National Conference of Catholic Bishops, and

many Papal Magisterium writings ensued. Each of these bodies delivered writings and opinions regarding the use of ordinary versus extraordinary procedures, weighing proportionate versus disproportionate effects, and determining burdens versus benefits in regard to the end of life and life-sustaining measures. While a clear-cut, black-and-white Catholic position statement cannot be found within these writings, the current document of consensus has been the Ethical and Religious Directives for Catholic Health Care Services (ERD) (United States Conference of Catholic Bishops, 2001). The most recent version of this document was adopted in 2001 and attempts to integrate all views regarding sensitive moral issues into unified ethical guidelines from which Catholic providers and Catholic-managed institutions can operate. The ERD speaks to the social, pastoral, and spiritual responsibilities of Catholic health care. Additionally, the ERD addresses the professional-patient relationship, issues regarding the beginning of life, issues regarding the end of life, and the type of relationships Catholics should have with other health care providers (United States Conference of Catholic Bishops, 2001).

The specific sections of the ERD devoted to end-of-life matters clearly address the use of life-sustaining measures. Directives 55-59 instruct the Catholic provider and patient to use ordinary and proportionate means to preserve life as long as benefit may be obtained from these means. The ERD also says that the forgoing of life-sustaining measures should be respected as long as there is no other conflict with Catholic moral teaching (e.g., euthanasia) (United States Conference of Catholic Bishops, 2001). In other words, there is always a presumption in favor of treatment as long as a personally perceived benefit exceeds physical, emotional, and spiritual burden.

While the American Bishops have declared the issues of burden and benefit as a suitable measure for life-sustaining measures, Pope John Paul II issued an Allocution in March 2004 (H.H. John Paul II, 2004) that seems to have complicated this issue for the American Church. In his Allocution, the Pontiff calls upon all Catholics to use artificial hydration and nutrition for anyone in a persistent vegetative state (PVS), especially when that person's desires regarding the end of life are not known. The Pope calls upon health care providers and surrogates not to use their own beliefs as the bases for making a decision for someone in a PVS. Rather, the Pope cautioned all faithful Catholics to use means to preserve life and choose options in favor of hydration and nutrition. This issue is not resolved and continues to be debated among the Catholic Church, particularly in America.

The Catholic Laity

While the Catholic leadership has come to some conclusions about withholding and withdrawing life-sustaining measures, the many groups that comprise the Catholic laity are not as cohesive in their opinions. The lay Catholic literature, including *Health Progress, Commonweal, Ethics and Medics,* and *the National Catholic Reporter,* espouses a variety of perspectives on issues surrounding death and dying. For example, Lustig (2003), a writer for *Ethics Watch*, calls for all Catholics to reflect upon their mortal lives so as to foster a greater sense of certainty about what is important in the limited time Catholics have on this earth. Lustig's position parallels that of Pope Pius XII, in that Lustig alludes to a promised afterlife. He refers to his perspective as emanating from an interest in "how to live authentically" from a point of faith (p. 7).

However, such moral high-ground is more likely to be the exception rather than the rule in the Catholic lay literature. Many Catholics who write about this issue take a definite opinion either for or against the withholding and withdrawing of life-sustaining measures. There is not one clear lay interpretation of the official teachings of the Catholic Church, and there seem to be confusing opinions about the ERD.

Recounting the story of her mother's death following several strokes, McCarty (1999) illustrates a struggle encountered by many who have desired to forgo life-sustaining measures. In the story, McCarty presents an account of fighting with her mother's nursing home administration and the nursing home's legal counsel, who desired to continue life-prolonging measures over and above the family's wishes. The family members desired to stop extraordinary means of prolonging life and allow their mother to die peacefully. In McCarty's article, all parties involved in the decisions regarding the patient were understood to be either of the Catholic faith or to be representing Catholic doctrine; both sides espoused opposite interpretations of the Catholic moral tradition in which the idea is to discontinue extraordinary means to prolong life.

The question of withholding or withdrawing artificial hydration and nutrition is often used as an example of the controversy surrounding the acceptability of forgoing life-sustaining interventions and is perhaps the most documented debate within the Catholic lay literature. The range of interpretations about the acceptability of this refusal of treatment varies considerably, even in the face of the ERD. The official interpretation of Catholic teachings allows for the forgoing of life-sustaining measures when the burden of any given treatment is in excess of the potential benefit to the patient. This more

modern stance, representing the official interpretation of American Catholic teachings, slowly seems to be emerging as the mainstream interpretation of end-of-life issues found in the American Catholic lay literature.

At the other end of the spectrum lies the view held by the vitalists or what some may call the more conservative faction within the Catholic faith. The vitalist perspective is one in which life is considered inviolate, and there is a decided preference in favor of artificial means to sustain life (May, n.d.). According to this perspective, life should be preserved at most costs with only some consideration paid to burden, benefit, experience, and faith interpretation (Province, 2003; Valko, 2003). Yet those with this opinion have been criticized within the Church. McCormick (1994) writes,

> Imagine a 300-bed Catholic hospital with all beds supporting PVS (persistent vegetative state) patients maintained for months, even years by gastrostomy tubes…An observer of the scenario would eventually be led to ask: "Is it true that those who operate this facility actually believe in eternal life?" (p. 232).

Even with the advent of the use of the ERD, the hierarchical nature of the Catholic Church allows for each individual diocese to explicate and interpret doctrine for its parishes and congregations. This is generally done through the issuance of some sort of interpretive statement from that region's archbishop. This can be seen most clearly in cases regarding hydration and nutrition within the Archdiocese of St. Louis, MO., in which Archbishop Justin Rigali issued such an interpretive statement. In his *Statement of Principle for Health Care Decision Concerning Hydration and Nutrition,* the Archbishop calls upon the words of Pope John Paul II:

> As ecumenical witness in defense of life develops, a great teaching effort is needed to clarify the substantive moral difference between discontinuing medical procedures that may be burdensome, dangerous, or disproportionate to the expected outcome--what the Catechism of the Catholic Church calls the refusal of overzealous treatment (no. 2278; cf. *Evangelium Vitae,* no. 65)--and taking away the ordinary means of preserving life, such as feeding, hydration, and normal medical care (Rigali, 2000, ¶10)**.**

In his concluding remarks, Archbishop Rigali's statement leaves readers with the impression that withholding or withdrawing artificial hydration and nutrition is still not acceptable. The following illustrates this issue:

> Pope John Paul II in his October 2, 1998 *Ad Limina Address* referred to *Nutrition and Hydration: Moral and Pastoral Reflections,* a 1992 statement by the National Conference of Catholic Bishops' Committee for Pro-Life Activities. The statement provides a thoughtful reflection on the issues, questions, theories and rationales for addressing this area of moral uncertainty. I recommend study of this statement by individuals and families that are confronted with questions regarding the moral appropriateness of continuing or withdrawing ANH [*sic*]. The conclusion of the Pro-Life Committee's statement still provides the best moral guidance on this question at this time (Rigali, 2000, ¶ 12).

Catholics' views are as varied as non-Catholics' and other Americans' views on these issues. In an effort to bring better understanding to this issue, the research study as conducted included the presumed influence of the Ethical and Religious Directives for

Catholic Health Care Services upon surrogates who engage in the withholding or withdrawing of life-sustaining measures in a Catholic intensive care environment.

SIGNIFICANCE TO NURSING

Some would argue that there is often conflict between the desires of persons who cannot participate in their own health care decisions and surrogates who must make end-of-life decisions (Terry et al., 1999). This conflict is witnessed by nurses every day around the United States in intensive care environments (White, Coyne, & Patel, 2001). Yet many nurses remain ill-prepared to handle the complexities of these situations, even with the development of additional education in the specialty (White et al., 2001; American Association of Colleges of Nursing, 2001). The idea of a specialized curriculum covering end-of-life issues has prompted the development of the End-of-Life Nursing Education Curriculum (ELNEC) (American Association of Colleges of Nursing, 2001) for baccalaureate nursing students.

Nurses and other health care professionals in intensive care environments often encounter and daily become involved with persons who become surrogates in decisions regarding withholding and withdrawing life-sustaining measures. Inherent in the nurse's role is his or her presence at the patient's bedside, with the patient's family, and often while the patient is in an intensive care environment (Hiltunen et al., 1999). Many intensive care practitioners are involved in intimate decision-making situations with surrogates who are faced with a decision of whether or not to forgo life-sustaining treatments such as cardiopulmonary resuscitation, artificial respiratory/ventilator support, artificial hydration, and artificial nutrition (Ivy, 1996). Yet little information about this

phenomenon exists to assist the health care professional in his or her support of the surrogate during the decision-making process (Truog et al., 2001). Thus, the research study as conducted is significant specifically to nursing and to those who must make decisions regarding the withholding and withdrawing of life-sustaining measures.

SPECIFIC AIMS AND GOALS

Despite the increased interest in issues surrounding death and dying in the United States, little research has been conducted and published relating to surrogate decision-makers who engage in the process of withholding or withdrawing life-sustaining measures in a Catholic intensive care environment. Hence, the goal of the study was to understand the process used by surrogate decision-makers who have made a decision to withhold or withdraw life-sustaining measures in Catholic intensive care settings. This study was accomplished through the use of grounded theory (GT) methodology.

GT methodology directs the researcher to collect the stories of the person or persons who experienced a phenomenon of interest in such a manner as to understand the processes used by the participants (Morse, 1994). In turn, this understanding is used to create a system of classifications leading to a theory about the phenomenon (Denzin & Lincoln, 1998). Consequently, the study included interviews of the surrogate or surrogates. Through constant comparison of the data, a theory was produced to describe the similarities in the process used by surrogates in making the decision to withhold or withdraw life-sustaining measures in a Catholic intensive care environment.

The goal of the study was to bring a greater understanding to the issues surrounding end-of-life decision making. GT methodology is used to explain process

questions (Morse, 1994) and, therefore, was best suited for this study. Strauss and Corbin (1998) offer this thought about qualitative methods: "Qualitative methods can be used to obtain the intricate details about phenomena such as feelings, thought processes, and emotions that are difficult to extract or learn about through more conventional research methods" (p. 11). In particular, Strauss and Corbin promote the use of GT methodology in the following manner: "Grounded theories, because they are drawn from data, are likely to offer insight, enhance understanding, and provide a meaningful guide to action" (p. 12). GT methodology was used because the researcher believed it offered the best possibility for accomplishing the intent of understanding the surrogates' decision-making processes. The researcher also hopes the results of this study will lead to further development of nursing interventions concerning end-of-life issues. The specific aim of the study was 1) to describe the process used by surrogate decision-makers who have made the decision to withhold and withdraw life support in a Catholic intensive care environment and 2) to develop a theory that explains this phenomenon.

ASSUMPTIONS

The assumptions of the research study were

1. The process of withholding or withdrawing life-sustaining measures commonly takes place in intensive care environments.
2. Surrogates are routinely a part of the decision to withhold or withdraw life-sustaining measures in intensive care environments.
3. The use of GT methodology is an appropriate method to discover the decision-making process used by surrogates who have engaged in the

withholding or withdrawing of life-sustaining measures in intensive care environments.

4. Surrogates who engage in withholding or withdrawing life-sustaining measures in intensive care environments will be willing to share their experiences.
5. Surrogates who engage in withholding or withdrawing life-sustaining measures in intensive care environments will be truthful in telling of their experiences.
6. The religious contextual influence of the most recent edition of the Catholic Church's Ethical and Religious Directives for Catholic Health Care Services may have had an effect upon the process used by a surrogate or surrogates who choose to withhold or withdraw life-sustaining measures in an intensive care environment governed by Catholic principles.
7. Nurses routinely work with surrogates who must make decisions to withhold or withdraw life-sustaining measures in intensive care environments, and thus the information obtained from the study may help to inform nursing practice.

LIMITATIONS

Qualitative investigational methods have unique limitations. Qualitative studies consider a specific group of individuals at a particular time in their lives, and the information obtained from those individuals is only as good as the respondent's memory or comfort level in disclosing information. Subjectivity on the part of the participants is unavoidable, and transferability is limited to groups similar to those depicted in a study.

Denzin and Lincoln describe the temporal nature of memory as "simultaneously focused in four directions: inward and outward, backward and forward" (1998, p. 158). Therefore, the study results presented here should be seen as applying to surrogates who looked at this experience in those four directions.

Additionally, the researcher is subject to his or her own biases and contextual meanings, which most certainly had an influence upon the research results. Grounded theorists are cautioned that it is impossible to leave one's biases outside the research and hence the results (Strauss & Corbin, 1998).

The Catholic context has placed additional limitations upon the study results. Given the religious influence of the Ethical and Religious Directives for Catholic Health Care Services, the study results may not have application outside a Catholic intensive care environment. However, use of this context has provided groundwork for future studies to examine the impact of secular and other non-religious institutional conditions on patients and surrogates who must make decisions to withhold or withdraw life-sustaining measures.

SUMMARY

The research study was intended to examine the process used by surrogate decision-makers in making the choice to withhold and withdraw life-sustaining measures in a Catholic intensive care environment. GT methodology was used as it was seen as the most appropriate methodological vehicle for the study. The results generated from this study were used to create a unified description of the decision-making experience that is expressed in the form of a theory.

All who work in intensive care settings, and particularly nurses, should have a vested interest in the knowledge obtained from such a study. Information obtained from this study may help ill-prepared practitioners to support surrogates engaged in the process of deciding to withhold or withdraw life-sustaining measures in intensive care environments.

The Catholic Church may find interest in the study, as there may be unrecognized religious influences operating upon those who must make these decisions. The Ethical and Religious Directives for Catholic Health Care Services document is intended to give the faithful and their health care providers some moral direction regarding end-of-life issues. Nurses often facilitated decisions regarding the withholding and withdrawing of life-sustaining measures in the study site. As facilitators, nurses are obligated to be informed about the information used by surrogates to make their decisions.

Surrogates who must make these decisions will find information from the study useful in guiding their processes, especially since little was known about the surrogates and their decision-making processes. While a "how-to" manual was not the desired outcome, a sharing of common experiences may be of comfort and benefit to any future surrogate who must act for the silent patient. Of all the reasons for this study, the desire to give voice to those who made these decisions was perhaps the most compelling.

CHAPTER 2

LITERATURE REVIEW

Introduction

While some researchers who utilize grounded theory methodology would argue that a literature review is contradictory to the method, an informed inquiry is warranted. Creswell (1994) observed that the qualitative researcher can use a literature review for a qualitative dissertation in three ways: 1) to create a background at the beginning of the introductory section, 2) as a separate section that will help to build a framework, and 3) to summarize at the end of the study in order to compare and contrast the research findings (pp. 21-22). Given this direction from Creswell, this chapter offers background that has informed the research study and defines the conceptual framework.

The work of Strauss and Corbin (1998) addressed the issues of literature review prior to conducting a grounded theory study:

> It is impossible to know prior to the investigation what the salient problems will be or what theoretical concepts will emerge. Also, the researcher does not want to be so steeped in the literature that he or she is constrained and even stifled by it (p. 49).

This reference is taken to mean that the researcher should not be biased by the literature in such a manner as to limit the questioning, and the literature should not direct the results of the emergent grounded theory. The data allow the theory to emerge as it is collected by the researcher. No a priori assumptions should be made about what the

theory will be. This is in keeping with Creswell (1994) in that the literature review is offered only as framework and background to the proposed study.

To set the stage for informing the research, the conceptual framework is discussed. This conceptual framework helped to inform the direction of the literature review and focus the selection of appropriate materials for discussion. This chapter is presented in two general areas: 1) the conceptual framework for the study and applications of the framework, and 2) related literature and research concerning the broad areas encompassed by withholding and withdrawing of life-sustaining measures.

CONCEPTUAL ORIENTATION-VEATCH

The conceptual basis for the study was Veatch's[1] guardian reasonableness standard. Bioethicist Robert Veatch developed a framework to measure the fidelity and veracity of an individual making medically related decisions on behalf of another person unable to participate in his or her own health care decisions. Veatch's standard states that surrogates should be afforded the same decision-making privileges that a competent person would in making his or her own decision to forgo treatment (Veatch, 1984). However, Veatch's standard is grounded in the assumption that the surrogate has a prior relationship with the person who is not able to make an independent decision regarding health care, especially in matters of forgoing treatment (Veatch, 1984).

[1] Veatch's writings about his conceptual framework predate the generally accepted use of the term *surrogate*. Veatch's original work in this area uses the term *guardian* to describe the person who is in a position to make decisions for another person who becomes incompetent or was never competent (Veatch, 1984).

The guardian reasonableness standard developed by Veatch is derived from deontological principles of ethics and case law. Veatch's guardian reasonableness standard attempts to define the decision-making role of an individual who is in a position to make medical treatment choices on behalf of an incompetent person, whether this incompetent person has never been competent or has recently become incompetent (Veatch, 1984). The concept of reasonableness is replete in every area of law, especially involving tort cases, and yet it continues to elude a clear definition, especially in the field of ethics (Veatch, 1984).

In many ways this standard is comparable to the currently accepted measures for surrogacy which involve the best interest standard and substituted judgment. Veatch did make reference to these principles in his writings and goes so far as to define these terms. Veatch (1984) defines the best interest standard as one which "requires the guardian [surrogate] to make a decision concerning treatment based on what is in the best interest of the patient" (p. 441) when the patient has failed to communicate their wishes preceding the time in which they are no longer able to make their own health care decisions. Veatch calls these patients "those without known views."

The substituted judgment standard is defined by Veatch (1984) for another group of patients which Veatch terms as "those with known views." He refers to the substituted judgment standard as "the mere execution of a decision the patient made while competent" (p. 439); the decision was communicated to the surrogate either in writing (such as an advance directive) or verbally in discussion. In Texas, the manifestation of the substituted judgment standard is the advanced directive (Tex. Health & Safety Code

Ann. §166.046, (Vernon, 1999)) and can be seen to document the patient's wishes prior to a time the person became incompetent to make personal health care decisions.

In decision making, any standard that involves reasonableness is not simply a matter of black and white or right and wrong and can be difficult to apply in a straightforward fashion. However, Veatch makes a convincing argument that reasonableness is the best standard to apply where the actions of surrogates are concerned. Veatch argues that a person who has had a prior relationship with a person who is no longer able to make his or her own health care decisions is superior in decision-making abilities compared to others who have not had such a relationship. Veatch calls this better-prepared category of person a "bonded guardian" (Veatch, 1984); he believes that health care providers should serve as consultants to these bonded guardians. Health care professionals should only intervene in the decision-making process when and if the bonded guardian seems to abuse his or her decision-making authority. If the surrogate is suspected of acting in a spurious manner, the health care team should seek the assistance of the courts in determining the reasonableness of the bonded guardian's decisions (Veatch, 1984).

Veatch (1984) refers to the constitutional right of an individual to refuse treatment as "premised on a right of privacy or a right to control one's body or a right of personal autonomy" (Veatch, 1984). In his later work, Veatch (2000) advances this idea to include surrogates under the "principle of autonomy extended" (p. 102), referring to the right of one person to choose for another under specific circumstances, such as a parent for a child.

Veatch (1984) takes extreme care to clarify the circumstances under which the guardian reasonableness standard should be applied. His discussion of guardians focuses on those who are known as bonded guardians and defines them as individuals who have had a significant relationship (prior to the time of surrogacy) with the person for whom they act:

> In short, bonded guardian decisions should be reviewed under a reasonableness standard. Under this standard, an unreasonable application of the guardian's admitted values and beliefs or a decision based on an unreasonable set of values and beliefs would be impermissible. A decision would not be unreasonable simply because it lacked popular acclaim; substantial leeway must be given decisions soundly based on tolerable values and beliefs. (p. 449)

Veatch delineates the role of the guardian under specific circumstances. The crux of withholding and withdrawing life-sustaining measures most often involves the *grave burden criterion*, which Veatch describes as a situation in which patient and surrogate's personal values allow the guardian to weigh the burden versus the benefit of a particular treatment. If the guardian feels that a given modality or therapy is a grave burden to the patient, no matter what the benefit might be, discontinuation of that treatment can be morally justified. Veatch (1984) outlines further qualifications for the guardian:

> Before grave burden can be adopted as a criterion for treatment refusal on behalf of incompetent patients, three findings must be established: first, that grave burden is a legitimate criterion for refusals by competent patients; second, that guardians have an obligation to serve the interests of their wards; and third, that

> the interest of incompetent patients in avoiding grave burdens are similar to those of competent patients. (p. 435)

On the other hand, if an intervention is considered useless based upon the goals of the treatment, then forgoing therapy should also be allowed. The useless criterion involves knowing what the end result of any and all life-sustaining measures should be. For instance, if the goal of an intervention is simply to prolong life with or without meaningful interaction of the patient with others, and a natural and peaceful death is a treatment goal, then withholding or withdrawing such interventions should be allowed (Limerick, 2002). However, Veatch goes on to say that guardian(s) for an incompetent patient should not be able to make unilateral health care decisions for an incompetent patient. Guardians must consider the wishes of those for whom they act, and Veatch maintains that there must be some attempt at justification by the guardian for the refusal of life-sustaining measures (1984, p. 428).

Veatch's framework focuses on the observable behavior of the guardian as influenced by his or her individual understanding of the patient's situation and personal evaluations. However, Veatch's framework for surrogates emphasizes the application of the right course of action for *another* (the patient), not necessarily the surrogate. This is not to say that the surrogate's own values are left out of the equation. Rather, the surrogate's values are taken into consideration as part of the outcome or decision-making process (Veatch, 1984).

Veatch's guardian reasonableness standard should only be applied within the context of surrogates who are making real-time decisions on behalf of a person who is

unable or incapable of participating in personal health care choices. Veatch believes that the context for guardian decision making can include individual(s) other than the surrogate, such as a health care provider who may have a role to play in the decision-making process. As such, Veatch's (1984, 2000) guardian reasonableness standard has application not only for surrogates and the persons for whom they make their decisions, but also for health care providers, ethicists, and the legal system, including the courts.

Veatch's guardian reasonableness standard has appropriate application to the day-to-day decision making of surrogates involved in determining whether to withhold or withdraw life-sustaining measures from an incompetent individual. This type of framework has the potential to allow most persons involved in surrogate decision making to understand how to explore what is best for incompetent individuals. Judgments of this magnitude are never made in isolation and are almost never clear-cut or black-and-white. It is often with ambivalence that the surrogate makes choices regarding the withholding and withdrawing of life-sustaining measures. Too often these types of decisions must be made in an American health care context that operates under a technological imperative, which defaults to doing *something* more, especially for the critically ill (Barnard, 1999) . As a result, nurses must include the surrogate, family, health care providers, and any other persons who may have a part in these types of decision-making processes. In summary, Veatch's framework is clearly relevant to a surrogate involved in decision making to forgo life-sustaining measures in an intensive care environment. Therefore, it has served as the conceptual basis for the research study and has informed the bases for the review of literature.

Veatch's Application to Nursing

While it seems plausible that Veatch's work would be aptly applied to the field of nursing, few have used Veatch's guardian reasonableness standard. One would think that his students would best apply Veatch's work. Sara Fry, a nurse and Veatch's protégé, focuses on ethical matters in nursing but with a decided emphasis on how nursing's and other disciplines' ethics differ (Fry, 1989; Fry, 1991;Fry, 1998; Fry, 2002). Fry's writings tend to be more philosophical in nature and not as empirically based, compared to quantitative and some qualitative research. Fry seems to have moved away from Veatch's traditional thinking of autonomy, beneficence, and justice (Beauchamp & Veatch, 1996; Veatch, 2000) and instead has moved toward a more feminist philosophy (Fry, 1989).

Penticuff proposed the used of Veatch's framework among parents who must make a decision to refuse life-sustaining measures for their critically ill infant (Penticuff, 1988). Penticuff's work applies the guardian reasonableness standard to parental decision making for infants and cautions health care providers to support reasonable parents through the conflict that may exist when making decisions to withhold and withdraw life-sustaining measures. Indeed, Veatch's original writings on the standard of reasonableness include application to parents and children as well as adults. However, the research focused on adults who must make decisions for adults.

Penticuff's writing about parental decision making for critically ill children is the only application of Veatch's guardian reasonableness standard found in the nursing literature. No researcher has applied the guardian reasonableness standard to adults in intensive care environments. This gap in the literature shows the need to examine this

phenomenon among adults in intensive care environments, and the application of Veatch's standard provided the necessary framework to conduct the research study in an area that has not been fully explored in the literature.

NURSING AND SURROGATE DECISION-MAKERS

The Robert Wood Johnson Foundation's influential Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatments (SUPPORT) (SUPPORT Principle Investigators, 1995) is often seen as a starting point when examining the literature surrounding surrogate decision making. The SUPPORT intervention took place between 1992 and 1994 among 2,652 patients in one of five teaching hospitals. Nine different diagnoses were included among the patient population. Nurses were given specific training to facilitate communication, provide support to families, and consequently improve decision making among patients, families, and health care providers (Murphy et al., 2000). The SUPPORT results failed to demonstrate that nurses had a significant effect in influencing end-of-life decisions and that surrogates did not dramatically change their viewpoints when facilitated discussions concerning end-of-life decisions were arranged (Baggs & Schmitt, 2000; Hiltunen et al., 1999; Lynn et al., 2000).

However, two factors should be considered when applying those results to today's environment. The first factor is the dated nature of the study. It was conducted over a two-year period in intensive care environments beginning in 1992. Additionally, the

Federal Government's Patient Self Determination Act of 1990[2] had not been fully enacted by most health care agencies as advance directives were still somewhat misunderstood by the lay public and the health care professions. To increase public awareness related to end-of-life issues since the original SUPPORT work, much has been done, such as the formation of organizations dedicated to improving the quality of the death experience. Organizations such as Last Acts (Zelman, 2000; Reichel, 1999) have raised the awareness of the inclusion of palliative care as a viable option for non-hospice patients and have influenced the inclusion of better end-of-life care (such as withholding and withdrawing of life-sustaining measures) (Scanlon, 2003).

Secondly, it has been suggested that the wrong intervention may have been used in the SUPPORT work (Murphy et al., 2001; Murphy et al., 2000;Lynn et al., 2000). The SUPPORT nurses were responsible for determining the patients' and families' desires with respect to communicating directly with the physician about end-of-life decisions and options, including forgoing life-sustaining measures. These decisions included consideration of therapeutic modalities such as may be seen in life-sustaining measures (Hiltunen, Medich, Chase, Peterson, & Forrow, 1999). The discussions about end-of-life preferences that were facilitated by the SUPPORT nurses have been criticized as not being sophisticated enough in terms of affecting decisions regarding end-of-life care, including withholding and withdrawing life-sustaining measures. Additional criticism

[2] The Patient Self Determination Act of 1990 requires health care facilities that receive federal funds to provide information about advance directives and to honor the decision making of legally designated surrogates such as a power of attorney for health-care.

concerning the SUPPORT intervention shows that the SUPPORT nurses did not have direct responsibility for obtaining the surrogate's and/or patient's decision(s) regarding end-of-life decisions.

Regardless of the effectiveness of the intervention, it is clear that this study showed the need to understand better the process used by surrogates to withhold and withdraw life-sustaining measures in an intensive care environment (Murphy et al., 2001; Murphy et al., 2000). Without a better understanding of the process used by surrogates, nurses are ill equipped to support the surrogate in their choices, including the withholding and withdrawing of life-sustaining measures.

INTENSIVE CARE ENVIRONMENTS

There is a need to examine intensive care environments because the majority of withholding and withdrawing of life-sustaining measures take place in intensive care environments (Swigart et al., 1996). The most complete reference related to research in the area of end-of-life decision making in the intensive care environment is summarized by Baggs and Schmidt (2000). Their discussion examined much of the current literature related to death and dying in an intensive care environment. The authors observed that most of the studies have been of a retrospective nature. Additionally, these authors noted that the interview of the person involved in the decision-making process was remote in time as to the actual decision making. Subsequently, there was support to conduct a study in which the interview was at an appropriate time relative to the process of making the decision to withdraw or withhold life-sustaining measures (Baggs & Schmidt, 2000). The work done by Baggs and Schmidt also argued, Although several groups and persons have

published guidelines for management of limitation of care decision and care of the dying patient, all were based on expert opinion; none was based in research data from the care settings" (p. 161).

While Baggs and Schmidt's expert opinion has involved physicians, nurses, and even some patients, end-of-life studies related to decision making in intensive care environments have not focused on the unique issues of the surrogate who is involved in the process of making the decision to withhold and withdraw life-sustaining measures. The lack of literature that has focused on the surrogates' perspectives gave direction to the researcher to explore this area more thoroughly.

SURROGATES AND WITHHOLDING/WITHDRAWING

Some researchers have focused their work on surrogates and the impact or experience of decision making to withhold and withdraw life-sustaining measures. However, this body of research has been concerned with a small subset of the broader area that comprises all of withholding and withdrawing of life-sustaining measures. Withholding and withdrawing of nutrition and hydration in the terminally ill and many of the ethical questions surrounding these decisions have been the primary foci of much of the literature (Goodhall, 1997; Mahoney, Riley, Fry, & Field, 1999; May, 1998; McIntosh, 1997; Pelegrino, 2000). However, none of the research has focused specifically on the surrogate's decision-making process nor has the setting been specific to a Catholic intensive care environment.

Some qualitative work has been conducted in the area of surrogate decision making. To understand surrogates' experiences, Jeffers (1998) studied 11 surrogates of

hospitalized patients and presented the results in four major themes. The surrogates contextualized their experience in terms of time and the medical environment and felt a sense of burden in shouldering the decision-making responsibilities. Surrogates in Jeffers' study also showed that the presence of advance directives did not give a clear sense of direction in the decisions to withhold or withdraw life-sustaining measures. Instead, the surrogates relied on faith, family, and prayer to help them get to a point of decision making concerning the end of their loved ones' lives.

Jeffers' (1998) study used phenomenology or the lived experience of the study participants to examine the decision-making process. As such, Jeffers' study gives limited comparative value to the conducted research, as the methodology used was grounded theory. Additionally, Jeffers' work used a narrow view of the potential available surrogates in that the study participants were all Caucasian and mostly well educated. However, the idea that faith based issues may have an influence upon the decision making of some surrogates provided a positive direction to the study as one of the defining characteristics of the research: the Catholic Ethical and Religious Directives (United States Conference of Catholic Bishops, 2001).

Other researchers have conducted studies related to the surrogate and decision making regarding life-sustaining measures for patients. Hiltunen, Medich, Chase, Peterson, and Forrow (1999) focused a study on the results of the SUPPORT nurses and the narratives they kept which described decisional conflict. However, the study done by Hiltunen and colleagues emphasized phases experienced by the surrogates as they attempted to make choices for those who were not able to participate in their own health

care decisions. Examination of 75 critical incidents showed themes which included surrogates recognizing problems for the patients, followed by surrogates' indecisiveness, and eventually a period when surrogates let go of the hope that the patient would survive or recover.

The work done by Hiltunen, Medich, Chase, Peterson, and Forrow (1999) showed that conflict exists for the decision maker when deciding for another individual. This perspective was presented from the point of view of the health care professional. As such, the study did not focus on the process of decision making from the point of the surrogate and did not study surrogates within an intensive care environment in a religiously based hospital setting.

The work done by Tilden, Tolle, Nelson, Thompson and Eggman (1999) was conducted with 30 family members of 18 deceased patients at one and six months following the death of the patient. Results of this study showed the influence of factors affecting the decision-making process to withhold life-sustaining treatment. The factors shown to influence the decision making included both the surrogates' abilities to recognize the state of the patients' futility and to reconcile this state against the patients' and families' values. Additional influences upon the decision-making abilities of the surrogates included the influence of clinicians and the receptiveness of surrogates to face decisions regarding termination of life-extending procedures.

Tilden and her colleagues described the study as one in which the process of decision making was examined. However, the results described the influencing factors upon the decision-making process and not the process itself. The study used ethnographic

techniques to describe the linear phases the surrogates pass through as a means to arriving at the point of decision making. While the study has relevance, it did not focus on the process of decision-making itself and was not conducted in a religiously based institution.

Work done by Tolle, Tilden, Rosenfeld, and Hickman (2000) examined responses from 475 family members who were involved in caring for a dying person during the last month of that person's life. The study was designed to look at barriers to the best possible care for dying patients from the families' perspectives. This study used a standardized structured questionnaire and was administered via telephone two to four months after the death of the patient. The study showed that family members expressed frustration with the lack of information and the inconsistency of information from their health care providers regarding the dying patient. This study did not examine the specific issues facing surrogates who have made the decision to withhold and withdraw life-sustaining measures in an intensive care environment. A focus upon any religious influence was also absent from this work.

Research done by Tilden, Tolle, Nelson and Fields (2001) studied the stress levels of surrogates of deceased persons and the contributing factors to that stress the surrogates encountered in making decisions to withdraw life-sustaining measures. Semi-structured interviews were conducted with families and health care providers to determine factors affecting rationale as it related to the withholding and withdrawing of life support. Using psychometric testing and short interviews, this study used a stress indicator tool, and surrogates were asked what stress item they found most influential upon their decision-making process.

The subjects in the study done by Tilden, Tolle, Nelson and Fields (2001) were contacted 7-10 days after the death of the patient in the intensive care unit, and subjects were asked if they desired to participate in the study at 1-2 months after the death of their loved one and again at 6 months after the death. The study used psychometric scales (Horowitz Impact of Events Scale and the mental emotional state scale of the Rand 36-Item Health Survey) to determine what contributed to the surrogates' stress in deciding to withdraw life-sustaining measures. This research showed that families experienced less stress in decision making related to forgoing of life support measures when an advance directive existed. Other findings included differences in reasoning among ethnic minority groups and reasoning differences among persons living greater distances from the hospital. None of the questions dealt directly with the process used by surrogate decision makers in deciding to withhold and withdraw life-sustaining measures.

Using work done by Tilden, Tolle, Nelson and Fields (2001), Norton, Tilden, Tolle, Nelson and Eggman (2003) conducted work that provided a subsequent analysis of a smaller subset of the larger group previously studied by Tilden and colleagues. Purposefully selected families who had experienced conflict with clinicians during the withdrawing of life support were interviewed using a qualitative descriptive methodology. The 20 family members who represented 12 deceased patients reported extensive needs related to communication from the clinicians as the family members made decisions regarding life-sustaining measures.

In a study conducted by Norton and colleagues (Norton et al., 2003), the participants were exclusively family members who had a known conflict during the

decision-making process. This differs from the conducted research study in that pre-existing conflict was not sought nor excluded for a study participant. Norton's study was conducted over two interviews and was descriptive of the conflict experienced and not of the surrogate's decision-making process. Using grounded theory methodology, the conducted research study described the process used by the surrogate decision maker in deciding to withhold and withdraw life-sustaining measures from an incompetent patient in intensive care. Norton's study certainly offers insight regarding how to communicate with family members who are in conflict during the decision-making process of withholding and withdrawing of life-sustaining measures, but it does not describe the process of decision making as was done in the conducted research study.

Work done by Hayes (2003) used phenomenology to study surrogates of patients who had experienced a devastating illness. In her study of 13 surrogates, Hayes found two major themes representing the experiences of the surrogates. Six to 18 months after the decision to withhold or withdraw life-sustaining measures from an incapacitated adult in intensive care, Hayes showed the surrogates to represent their experience in terms of "representation of other and memory manipulation" (p. 91). Hayes' study results also showed that the surrogate's experience of the decision-making process was not linear and involved iterative steps.

Hayes' (2003) study used phenomenology to study the experience of the surrogates in deciding to withhold and withdraw life-sustaining measures. As such, the study had some comparative value to the current research study. However, one of the demographic markers used in the study done by Hayes showed that 92% of the study

participants were Catholic as were most of the patients for whom they made decisions. Hayes did not focus the study to explore the experience of the surrogates from the Catholic experience, and the Ethical and Religious Directives of the Catholic Church were not explored for their influences upon the surrogates' decision-making processes.

The studies by Tilden, et al (2001), Tolle, et al (2000), and Norton, et al (2003) provided significant findings regarding barriers, stress, and conflict, especially as any one of the variables relates to communication needs among surrogates. Hayes' (2003) work gave credence to a supposition that the surrogate's experience is most likely iterative and multi-factorial. Jacob's (2003) study described the experience of family members who were involved in the decision to withhold and withdraw life-sustaining measures. However, none of these studies focused on the process of the surrogate when making the decision to withhold and withdraw life-sustaining measures, and few focused on the intensive care environment. Additionally, none of the studies focused on an overlay of religiously based health care as is seen in some Catholic health care facilities.

The issues of stress and communicative needs in surrogates have been studied by other investigators. Work done by Kahn and Steeves (2001) studied stress encountered by surrogates during the process of defining a good death for the patient and surrogate. Aesthetics is discussed in a case-study-presentation model to help health care providers understand the view of the patient and family in making decisions concerning end-of-life care. This case presentation is of one patient and her family and does not specifically focus on the decision-making process of the surrogates. This patient was hospitalized numerous times prior to her death, but she died in her home. Kahn and Steeves' findings

gave limited direction to the conducted research study; however, this case does bear some discussion.

This study showed the complex nature of decision making and the multi-factorial problems families and patients encounter. In some ways, this case study presentation is a microcosm of the larger world described by other researchers dealing with end-of-life issues. Kahn and Steeves' case study presentation showed the need to continue to investigate the issues around surrogate decision making. These authors offered this admonition to the nursing community and cautioned against attempts to fully define and generalize one person's experience to others: "But abstraction to the point of prescription seems impossible, unrealistic, and counterproductive when attending to individuality, uniqueness, or the 'suchness' [*sic*] of people lives and deaths" (2001).

Spirituality emerges as a theme in the case study. The spouse of the patient at the center of this case study was shown to face a crisis of faith in watching his wife die. The patient's husband wrestled with his issues through a personal sense of faith and successfully resolved his questions of human suffering within his belief system. Kahn and Steeves (2001) advised those in the areas dealing with care for the dying to become proficient in recognizing spiritual issues and making an appropriate referral to a qualified spiritual counselor. While spirituality is not the same as religiosity, the parallels can be seen for surrogates who find strength in involvement with some higher moral power. This would be in keeping with the conducted research study with its areas of interest including the Ethical and Religious Directives of the Catholic Church (United States Conference of

Catholic Bishops, 2001) and whether or not the document influenced surrogates who made decisions to withhold and withdraw life-sustaining measures.

Kahn and Steeves' (2001) admonitions are good advice to the researcher who wishes to embark upon investigations of surrogates. Kahn and Steeves, among others, have helped to shape the course for investigation into the matters around the end of life. For instance, the concept of suffering (Kahn & Steeves, 1994; Kahn & Steeves, 2001) has been discussed as universal in the area of end of life. As a result of the research conducted by Kahn and Steeves, nursing research has been expanded concerning how to deal with populations who suffer (patients), how to help those making decisions about the final days of life (patients and surrogates), and how to deal ethically with the bereaved (Steeves, Kahn, Ropka, & Wise, 2001). While Kahn and Steeves' work has helped to inform the conducted research study, the study has helped to close the gap in the literature and has added to our understanding about surrogates and the decision-making process.

THE CATHOLIC VOICE

Consideration was given to research and writings that were supported by the Catholic view of similar issues. This was done to understand the breadth of the gap in the literature. Looking to researchers with a decided Catholic view offered further direction to the conducted research study. Daniel Sulmasy, a Franciscan friar, holds a medical degree and a doctorate in philosophy. Sulmasy has conducted research dealing with the accuracy of judgments by surrogates (Sulmasy et al., 1998), consideration of patients and surrogates who disagree concerning end-of-life treatment (Terry et al., 1999), and issues

around comfort at the end of life (Jansen & Sulmasy, 2002). Sulmasy has also discussed the role of religion in patients who face life-threatening illness (Kub et al., 2003; Sulmasy, 2002)

The best application of Sulmasy's work to the conducted research study involved the accuracy of judgments by surrogates (Sulmasy et al., 1998). In this study, Sulmasy and his colleagues worked with 250 outpatients with one of five terminal illnesses. Fifty surrogate pairs were selected from each of the five disease classifications, and 50 more surrogates were selected from a general medical group. The surrogates were asked to predict the patients' preferences for 10 potential treatments in three different hypothetical clinical situations. Each of the three clinical vignettes was used to be predictive of the patients' desires, and then those results were measured against the surrogates' decisions to forgo life-sustaining measures. A 66% accuracy rate was found between what the surrogates predicted that patients would want and what the patients actually desired as to life-sustaining measures. Several factors were found to correlate with high agreement between the surrogates' and the patients' desires. When the education levels of surrogate and patient closely approximated, the decision was found to be more closely aligned between the surrogate's choice and the patient's choice for end-of-life care. Additionally, when the surrogate's participation in organized religious services and the surrogate's prior experience with life-sustaining measures approximated those of the patient, agreement about life-sustaining measures was also more likely. While this research by Sulmasy and colleagues informed the conducted research study, Sulmasy's work did not

focus on the surrogates' decision-making process and did not examine this phenomenon in a Catholic intensive care environment.

USE OF GROUNDED THEORY METHODOLOGY

Grounded theory methodology has been used to examine the experience of surrogate decision makers in intensive care areas. Research done by Swigart (Swigart et al., 1996; Swigart, 1994) was conducted with families as they made decisions to withhold and withdraw life-sustaining measures. Grounded theory methodology was used to conduct these studies, and the results showed that the surrogates made decisions over time and in an iterative fashion. Swigart's study results showed that surrogates had to fulfill multiple needs (need for time, need for understanding, need for information, etc.) before being able to make a decision regarding the withholding of life support. An essential message concerning Swigart's (1994) research is shown in the following:

> This research supports the notion that family members participate in life support decision making using knowledge from personal experience, ethical beliefs, and aesthetic assessment, in addition to scientific medical information. The families in this study used substituted judgment and best interest as ways of deliberating about life support… (p. 158).

Swigart's work cited the use of divine intervention as the primary method of decision-making process used by some surrogates and, for other surrogates, the decision not to make a decision at all. The importance of the family unit and make-up of the family relationships were also revealed in this study. However, Swigart conducted her study in a large university hospital. Her study was conducted in real time in a medical

intensive care unit and most often involved multiple decision makers for a single patient. The surrogates were asked to participate in the study while the critically ill patient was under consideration for removal of life-sustaining measures. It is possible that the study participants did not have time to reflect on the process of decision making and might have provided Swigart with different results had the study been conducted at a time further removed from the decision-making process.

The conducted research study differed from Swigart's research in that the study participants were interviewed no sooner than three months following the withholding and withdrawing of life-sustaining measures. The hospital setting where the critically ill patients received care was a Catholic managed hospital and was not affiliated with a major university medical teaching program. Patients for whom surrogates made the decision were not be limited to any one critical care area such as a medical intensive care but could have received care in a number of intensive care environments.

Research done by Jacob (1998) studied 17 family members of incompetent patients in an intensive care. This study used GT methodology to examine the family's experiences as they moved through the decision-making process on behalf of a critically ill love one. Jacob found that family members had a need to work with health care givers and to make sure the decisions regarding limitations of life-sustaining measures were enacted. Jacob's study showed that surrogates used information from health care providers, patient prognoses, and physical cues from the patient (unresponsive or comatose) to arrive at a judgment concerning the patient's condition. Surrogates had a distinct sense of "moving in concert versus disharmony (p. 33). Jacob's work has

suggested that when a decision maker had a harmonious relationship with all health care personnel who provided care to a loved one, then the decision maker had less guilt, and the decision maker also perceived the patient received quality health care. Jacob's study also showed that the surrogate looked back at the patient's life, then to the present condition, and finally to the future. This temporal sense helped the surrogate to make decisions regarding the limitations of life-sustaining measures.

While Jacob's (1998) study used GT methodology to examine this phenomenon, Jacob described the objective of the study as: "To describe and explain the experiences of family members who were involved in decisions on behalf of their loved ones in order to promote understanding of such experiences and to suggest areas for effective, supportive intervention" (p. 30). Given this stated objective, Jacob's research had only limited application to the conducted research study. The study by Jacob did not focus on the process of decision making but instead was intended ultimately to assist health care providers with supportive techniques to the surrogate involved in the decision-making process. The conducted research study was intended to describe the process of decision making used by surrogates who made the decision to withhold and withdraw life-sustaining measures in a Catholic intensive care environment.

Norton' s (1999) work also used GT methodology to study one aspect associated with surrogate decision makers. In her study of 20 participants, Norton interviewed patients, surrogates (termed *families* in the study), and health care providers (physicians and nurses); she studied how these groups collaborated with each other to make decisions regarding treatment options at the end of life. However, 15 of the 20 interviews used in

this study were from healthcare providers and resulted in data showing the influence of the professional provider upon the family decision maker. This influence was especially pronounced when the providers felt that the family had unrealistic goals of care. Data from the family interviews suggested that health care providers had significant influence on family decision making in terms of withholding and withdrawing life-sustaining measures. The providers in Norton's study were found to avoid discussion with families, refer families to other providers, and to attempt reconciliation of unrealistic goals of care with the actual care being received.

The issues raised by Norton represented one side of the discussions that take place in end-of-life situations and primarily focused on the health care provider. The surrogate's view was poorly represented in the study, and the emergent theory expressed the issues in terms of a negotiation between the health care providers and the health care recipients. Like Kahn and Steeves' (2001) work, the study's intent was to assist providers in developing supportive strategies for those facing the end of life. In the planning stages for the conducted research, a potential outcome was the possibility of developing supportive strategies for surrogates. However, the conducted research study concerned the development of a theory to explain the process of decision making used by surrogates who have made the decision to withhold and withdraw life-sustaining measures in a Catholic intensive care environment.

GRIEF, BEREAVEMENT, AND REMEMBERING

To understand the potential effects of the changing nature of grief and bereavement and its association upon the surrogates' experiences, some definitions are in

order. Bereavement is the state in which the bereaved expresses his or her feelings of loss. Grief is the emotional display of the bereaved state. (Sprang & McNeil, 1995; Corless, 2001). It is the emotional display that is most likely to have an impact upon the accurate reporting of events (Addington-Hall & McPherson, 2001) regarding the surrogates' experiences of withholding and withdrawing of life-sustaining measures.

Grief displayed during the bereaved state is a process that undergoes dynamic changes over time (Addington-Hall & McPherson, 2001; Danforth & Glass, 2001). Using the Texas Revised Inventory of Grief (TRIG), research done by Ringdal, Jordhøy, Rindgdal, and Kaasa (2001) showed a relatively flat graph of the TRIG scores from 1-3 months following the death of a loved one. At the three month period, the bereaved individual began to show a steady decline in the TRIG score until one year after the death. This was true of the research whether the deceased and the surrogate or family had participated in palliative care or not.

Further, there is some evidence to suggest that remembering is influenced by the individual's perspective. The less time between the event and the recall of the event, the more accurate the portrayal of those events is likely to be (Addington-Hall & McPherson, 2001). Therefore, the conducted research study design delineated the contact with the surrogate as no sooner than three months and no later than one year following the death of the loved one. This aspect of timing of interviews for the surrogate is further discussed in the methodological chapter.

SUMMARY

The review of the relevant literature has shown a gap concerning the process that the surrogate uses to make a decision regarding withholding and withdrawing of life-sustaining measures for the incompetent patient in the intensive care environment. Additionally, none of the research focused specifically on a Catholic intensive care environment. This gap in the literature gave support for the need to conduct this type of research with surrogates of the critically ill, adult patient in intensive care and in a Catholic environment. Additional understanding of this phenomenon will affect the quality of care for the terminally ill patient through the effective support of the surrogate by helping members of the health care team to understand how these types of decisions are made.

This area of research can contribute to more effective care of the dying and the surrogates who are often faced with the decisions regarding life-sustaining measures. Specifically, this study will help the nursing and other health care professions understand the decision-making process of surrogates who must decide whether to withhold and withdraw life-sustaining measures for an incompetent patient while in an intensive care environment.

CHAPTER 3

METHOD

Introduction

The purpose of this chapter is to explain the use of grounded theory (GT) to explore the process used by surrogate decision-makers in making decisions to withhold or withdraw life-sustaining measures in a Catholic intensive care environment. This chapter will provide an overview of GT as a methodology and explain the method's suitability for the current study and research question. Details of the study design, such as participant risks, access to participants, and informed consent, will then be presented. Other methodological issues, such as sample selection, data collection procedures, bias control, rigor and trustworthiness, and protection of participants, will be detailed. A section describing the study's participants and a section describing the influence of the researcher on the study is also included.

GROUNDED THEORY BACKGROUND

Grounded theory methodology originated in the field of sociology. Glaser and Strauss, two sociologists working in the early 1960s, argued that theories or hypotheses should not necessarily be proven by data, but rather that data should allow a theory to emerge inductively (Bailey, 1997; Day, 1999). Glaser and Strauss (1967) sought to demonstrate that explanations about phenomenon are more salient when generated from data rather than when established through a priori assumptions. This directly contradicted the prevailing and scientifically accepted methodologies of the 1960s, as can be seen in

the following excerpt from a later explanation of GT by Strauss and Corbin (1998, p. 1440):

> Theory derived from data is more likely to resemble the "reality" than is theory derived by putting together a series of concepts based on experience or solely through speculation (how one thinks things ought to work). Grounded theories, because they are drawn from data, are likely to offer insight, enhance understanding, and provide a meaningful guide to action (p.12).

GT has become a well-established methodology within the rubric of scientific investigation known as qualitative research, which addresses questions of identification, description, exploration, explanation, or prediction and control (Polit & Hungler, 1999). Denzin and Lincoln argue that qualitative research "implies an emphasis on process and meaning that are not rigorously examined or measured (if measured at all), in terms of quantity, amount, intensity, or frequency" (1998, p. 8). In light of the fact that the current study is devoted to identifying and describing surrogate processes, as opposed to quantitatively measuring the phenomenon, a qualitative methodology was deemed not only appropriate but also necessary.

This is not to say that qualitative methods are foolproof. Choosing one method over another can present challenges to researchers. When using qualitative research, methodological differences are often difficult to discern, and this can lead investigators to utilize a hodgepodge of methods within one study (Baker, Wuest, & Stern, 1992). GT is not exempt from such confusion. When researchers manifested difficulty understanding and applying the specifics of GT, Glaser (1992) wrote a rebuttal to what he interpreted as

the bastardization of Strauss' and his original method, as later espoused by Strauss and Corbin. Even the originators of the GT method have confusions about GT's applications and what it really means to utilize the approach in research (Glaser, 1992). Whether a researcher subscribes to one particular interpretation of GT over another, it can still be said that Glaser and Strauss, along with Strauss and Corbin, emphasize the process of inductive theory development or emergence of a theory from the data.

Qualitative methodologies share numerous similarities, particularly their reliance on non-quantified investigation of phenomena through narrative data. Nevertheless, each specific method within the corpus of the qualitative literature has its own unique use (Polit & Hungler, 1999). Agar (1999) argues that "qualitative" should be an umbrella for a family of methods, such as GT, that are distinct from one another in ways that are often difficult to discern and that are similar to one another in much the same way that siblings of the same family are. Bailey illustrates this idea by introducing the analogy of over-the-counter pain medications; although aspirin, Tylenol®, and Bufferin® may be used interchangeably, each is unique and has specific uses (1997). It has been argued that GT is best used for the development of theoretical constructs (Bailey, 1997), and thus it offers the researcher a method that can give rise to the emergence of a theory. Theories derived from GT seek to explain a phenomenon or experience through the observation of processes that are guided by the genuine expression of participants' perspectives.

Most researchers argue that one's research question should inform one's choice of method (Straus & Corbin, 1998). One cannot, therefore, select one method in favor of another without a complete understanding of what is hoped to be accomplished through

the proposed research (Byrne, Kangas, & Warren, 1996). Roter and Frankel (1992) found that "the form a question takes – that is, open or closed, direct or indirect – has consequences for the kinds of information it is likely to elicit" (p. 1100). The kind of information that GT is likely to elicit serves to answer to questions of process. This is the principle feature that differentiates GT from other qualitative methods.

Morse (1994) provides guidelines for making a determination as to which type of methodology is best suited for various kinds of qualitative research. Morse writes with a definite bias in favor of GT when the researcher is examining a phenomenon in which process issues predominate. Morse feels that GT is especially useful when studying a phenomenon experienced by subjects over time or in stages or phases (1994). Further, Morse offers this direction in the choice of qualitative methodology: "If the question concerns an experience and the phenomenon in question is a process, the method of choice for addressing the question is grounded theory" (p. 223).

Thus, GT can be used by researchers to develop an explanation and possible prediction of behavior within a given context (Annells, 1996; Morse, 1994; Polit & Hungler, 1999), and it aids the researcher in the attempt to discover the essential societal drive influencing human action (Thorne, 1991, p. 200). The researcher who uses GT endeavors to explain the meaning of behavior or processes through the development of categories that can later be linked to explain or predict the behavior of study participants. The categories are linked in such a way as to allow for the emergence of a theory.

Defining Characteristics of Grounded Theory

The researcher who uses GT is required to adhere to a specific set of guidelines in order to assure the accurate representation of the reality of those individuals included in any given specific research project (Polit & Hungler, 1999). Several of these guidelines will be discussed including constant comparison of the data, attention to participant voice, theoretical sampling, and trustworthiness which includes the use of timely field notes, auditing, and publication of results.

One of the most noteworthy defining characteristics of GT is the constant comparison of the data with categories that emerge from the data (Day, 1999; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Data are collected by face-to-face interview, recorded on either audiotape or videotape, and transcribed word for word. This is followed by several line-by-line readings of the data transcripts. These line-by-line readings allow the researcher to code or categorize the similar basic themes that are commonly found during examination of the study participant's transcripts. This iterative process is continued with each interview or new piece of data until no new categories emerge. Moving from the concrete to the abstract (Denzin & Lincoln, 1998), the researcher utilizing GT engages in the iterative extraction of information until saturation of information is reached and no new information is discovered. This saturation point is thought to be most predictive of the phenomenon under consideration and will produce an explanation of the data as it relates to the study subjects (Strauss & Crobin, 1998). Categories leading to themes can be linked together in a systematic way, which leads to

the construction of a theory or explanation about the phenomenon under consideration (Strauss & Crobin, 1998).

The study subjects may provide the researcher with additional sources of information such as dialogue exchanged around other text, personal pictures, musical recordings, or poetry. Study participants who give in-depth descriptions of their own stories and contribute to the research with additional text add "voice" to the study data, and attention to this is a crucial component of GT research. Voice, as conceptualized by proponents of GT, is the accurate and adequate representation of the sample in such a way as to convey a personal experience from the perspective of the study participants (Denzin & Lincoln, 1998).

GT differs from other qualitative methods in its use of "theoretical sampling." This term refers to the process by which the researcher collects data and continually reviews it, allowing a theory to emerge. Purposeful sampling of different or select groups to identify similarities and differences within the information gleaned from subjects directs the researcher's decision about where, what, and who should be sampled or interviewed next (Day, 1999; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Theoretical sampling provides the researcher with a certain amount of structure and simultaneously a degree of freedom, as each new step is guided by the data and by the theory as it emerges from the data. Strauss and Corbin (1998) offer this explanation of theoretical sampling: "The aim [is] to explore the dimensional ranges or varied conditions along which the properties of concepts vary" (p. 73). Hence, the GT researcher

investigates a process through purposeful sampling of those most likely to inform the study best.

In order to assure trustworthiness of the results, the researcher using GT is advised to provide adequate documentation to allow for audit and review of study data. When using GT, the researcher is to include written notation about the field environment, such as the time, place, and setting of the interview and details about the individual subjects (Day, 1999; Glaser & Strauss, 1967; Strauss & Corbin, 1998). The purpose of this is to provide an accounting of non-verbal (not on audio or video tape) and environmental influences that may aid the researcher in developing a more robust set of categories and themes. Additionally, these field notations allow for reviewers outside the study to critique the researcher's conceptualization of the emerging theory. Use of this paper trail by the researcher and outside reviewers assures greater accuracy in the interpretation of the data and allows for an increase in the trustworthiness of the results.

An external reviewer, or someone familiar with the subject but not directly involved in the research, typically completes an additional review of the study data. The outside reviewer is most often chosen for his or her expertise in interpretation of qualitative data, preferably GT. Examination of the researcher's field notes and results by this outside auditor can yield an opinion contradicting the researcher's findings. However, if the external auditor interprets the data and field notes and reaches the same conclusions as the researcher, corroboration of the results and increased trustworthiness is obtained (Polit & Hungler, 1999, p. 5450).

Publishing research results allows the application of the GT methodology and the results of the study to be scrutinized by the public. Publication alone, however, is not sufficient to guarantee the accuracy of research results. Inevitably, questions will remain as to whether the ideas the researcher chose to articulate in the research results truly represented the experiences of the subjects. What subjects do not say, for example, is often just as important as what was actually articulated to the researcher (Denzin & Lincoln, 1998). Moreover, a researcher's own biases and interests can affect a study's conclusions. For instance, if a researcher had a preference for feminist or Marxist views, the study's results might incorporate different essential qualities and meanings than what the subjects in fact meant to express. It is the researcher's responsibility to assure that what is published in textual format accurately and realistically portrays and represents the experience of the informants of the research (Denzin & Lincoln, 1998). The most common method chosen to demonstrate study accuracy is publication of the study results in a journal that is read by scientists of like or similar disciplines. In this manner, others who have had experience in research closely aligned with the publishing researcher serve to critique the study design, methodology, and results.

GT as an Appropriate Methodology for the Research

One of the most compelling reasons for the use of GT in this study lies with GT's history. The originators of the method, Glaser and Strauss (1965, 1967), studied issues related to dying. Their work in this area gave rise to the formal development of GT. More recently, Swigart (1994) used GT to examine the process of family decision-making regarding life support. Norton (1999) used GT to study the process of negotiating

decisions near the end of life, and Jacob (2003) used GT to study families who made decisions on behalf of incompetent intensive care patients. Given that the research study is concerned with similar processes, namely surrogates' decisions to withhold or withdraw life-sustaining measures in intensive care, GT appears uniquely suitable.

Insights obtained through the use of GT have helped to develop an understanding about the processes used by surrogates who make decisions regarding forgoing life-sustaining measures. Results that might be obtained through other qualitative methods are not less valuable. However, of greater importance to this research is the explanatory and predictive power that GT results may offer about the surrogate decision maker's process related to withholding or withdrawing of life-sustaining measures in a Catholic intensive care environment.

The results from the study may have other explanatory and predictive applications. Findings from the current study may help to inform nurses as they support surrogates who engage in the process of making the decision to allow withholding or withdrawing of life-sustaining measures in a Catholic intensive care environment. For instance, the results might predict the optimal time for surrogates to make decisions regarding withholding or withdrawing of life support. The study could assist in future interpretations of Catholic doctrine for the lay community as it relates to end-of-life care and also help to inform policy and regulatory interpretations surrounding the issue of withholding and withdrawing of life-sustaining measures.

METHODOLOGICAL ISSUES ASSOCIATED WITH SOCIALLY SENSITIVE RESEARCH

The hallmark of modern research is informed consent, as set forth in the Belmont Report of 1979. The Belmont Report identifies the basic ethical considerations that must govern research, including respect for person, beneficence, and justice. It also provides specific guidelines for conducting investigations, such as obtaining informed consent, assessing the risk and benefits of the research, and appropriately selecting subjects (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). In deciding to use GT as the appropriate method for the study involving surrogates who have been involved in the decision to withhold and withdraw life-sustaining measures, the researcher was required to exercise cautious respect for persons belonging to a *vulnerable population*, defined as a group of people who may be exposed to greater than *minimal risk* during the research process (e.g., those with mental retardation, children, pregnant women, and comatose patients) (Polit & Hungler, 1999, p. 5450). According to the National Science Foundation (2001), minimal risk is defined as ”The probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests" (p. 244).

As research participation required that subjects engage in an activity that was not part of their daily lives and prompted them to recall memories of emotionally stressful information (Orb, Eisenhauer, et al., 2000, p. 110), the surrogates who were interviewed were treated as if they comprised a vulnerable population. In order to protect these

vulnerable people, the researcher took particular care with the study participants throughout the interviews. This was accomplished through multiple verification points during the conversations (Swigart, 1994, p. 3340), in which the participant was asked if she or he felt like continuing to answer questions. The study participants were informed that they could elect to stop their participation at any point.

Orb, Eisenhauer, and Wynaden (2000) caution the nurse researcher to adhere closely to ethical principles when conducting qualitative studies. These authors advise all qualitative researchers to be aware that "recurrence of 'old wounds' and sharing of secrets" may mark participation in research and that "the interview opens new risks to both researcher and participants" (p. 94). This proviso prompted the researcher to pay particular attention to the vulnerable population being studied and to address the risks to participants during the investigation.

Participant Risks and Protections

The loss of a loved one is fraught with issues of grief and bereavement that may go on for many years. Indeed, many who experience the loss of a loved one continue "a bond with their dead indefinitely" (Walter, 1999, p. xiii). It is possible that grief and bereavement were still present among participants during the time the interviews were conducted. During study interviews, some participants could become distressed or anxious as a result of reliving experiences related to the experience of withholding or withdrawing life-sustaining measures. To assure that all participants would have access to qualified grief services, a referral from the researcher for grief support groups was available to all study participants. In addition, a local hospice organization agreed to

accept grief-counseling referrals for participants who became distressed as a result of their study participation. These support group services were provided free of charge to any subject regardless of the person's prior, current, or future involvement with the hospice organization.

The recruitment procedure for the study involved many safeguards for the potential participants. The initial contact with the study participants was through a letter from the researcher and the intensive care environment nurse managers. However, the potential participants had control over whether they were subsequently directly contacted. Direct contact was made with a surrogate who had been involved in withholding and withdrawing life-sustaining measures only after the surrogate chose to contact the researcher. Elements of informed consent were included in the cover letter sent to the potential study subject (see Appendices C1 and C2), and participation was purely voluntary.

Additionally, all identifying information regarding the surrogate and his or her family was disguised or represented by pseudonyms in the transcripts of the interviews. In this way, any materials presented in written format would safeguard the study participant’s identity and right to continued privacy after conclusion of the formal study.

Given that the study examined the potential influence of Catholic doctrine upon decisions to withhold or withdraw life-sustaining measures, it was crucial that approval was granted by the agency where the research subjects were identified. Without the agency’s support, the current study could not have been conducted. A letter written in support of the study by the agency is included in the appendix (see Appendix A). The

study was then presented to the Departmental Review Committee of the University of Texas at Austin's School of Nursing for approval. This body attested to the safety and sound science of the study and afforded the study participants another level of protection. Finally, the study went before the Institutional Review Board for the University of Texas at Austin and was scrutinized for adequate protection of human subjects.

While the risks to study participants were by no means insignificant, the knowledge produced as a result of the investigation potentially affords others in a similar situation with better informed nursing support. In addition, nursing as a discipline is offered enhanced insight into a process that has not been well understood. This insight will hopefully lead to better support of those served by nurses who witness decisions to withhold and withdraw life-sustaining measures.

Access

It is challenging to gain access to a population of persons who have acted as surrogates in deciding to withhold or withdraw life support in a Catholic intensive care environment. However, the local Catholic health care system, where the surrogates made the decisions to withhold and withdraw life-sustaining measures, agreed to allow access to data systems with information about potential study participants.

To be included in the study, a surrogate must have made a decision regarding the purposeful act of refusing consent for life-sustaining measures and/or must have made a decision regarding the purposeful act of removal of life-sustaining measures for an adult patient who received care while a patient in a Catholic intensive care environment. The surrogate may have been legally designated, such as in the case of a court-appointed

advocate, or legislatively directed to act for a person incapable of participating in his or her own health care decisions, as specified in the Texas Health and Safety Code (Tex. Health & Safety Code Ann. §166.046, (Vernon, 1999)). Persons fulfilling the surrogate's role did not need to be related to the person for whom they made withholding and withdrawing decisions. However, all of the surrogates in this study were related to the patient by blood or marriage.

The Catholic hospital system's involvement in the study was limited to support of the researcher in the identification of persons who received care in one of the system's intensive care environments. These areas included the intensive care unit, the intermediate care unit, the emergency department, trauma services, and the cardiac telemetry unit. Patients in these units were qualified to receive one or more life-sustaining measures but did not necessarily receive any of them. Life-sustaining measures included, but were not limited to, artificial ventilation, artificial hydration and the devices necessary to deliver it, artificial nutrition and the devices necessary to delivery it, surgical interventions, cardiopulmonary resuscitation, medications to control heart rate or blood pressure, blood and blood products, hemodialysis, and chemotherapeutic agents. The surrogates for patients must have made a decision to withhold and withdraw one or more of the life-sustaining measures.

Lynn et al. (1997) have suggested that the optimal time for contacting surrogates for study participation is 4 to 10 weeks after the death of the patient. More recent research shows that surrogates tend to participate in research between three and six months after the death of a loved one (Teno, Clarridge, et al., 2000), and rarely do

surrogates wish to decline participation in such studies (Fowler, Coppola, & Teno, 1999). Given the variable time range in researching this population, letters were sent to the surrogates no sooner than three months and no longer than one year following the withdrawing and withholding of life-sustaining measures.

Informed Consent

The specifics of informed consent are outlined in The Belmont Report (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). The Report delineates the rights of the researched and the responsibilities of researchers involved in studies with human subjects. The Belmont Report clearly directs researchers to obtain informed consent for participation from study subjects. It also stipulates that researchers must provide information about the study to participants in a manner that leads to their comprehension of the risks and benefits of the research and of the voluntary nature of their involvement. Specific attention is to be paid to the appropriate selection of subjects, and cautionary statements should be delivered to those who represent members of vulnerable populations. Preventing the appearance of coercion is necessary to assure the complete voluntary participation of all study subjects.

The personal nature of the information obtained from this particular study population required great discretion so as to assure absolute confidentiality and anonymity of subjects. Disclosure of the study information in a manner that could identify participants would have been unacceptable, and so procedures designed to safeguard their confidentiality were required. The process of informed consent demonstrated to the participants that every precaution was taken to protect their

confidentiality. For example, participants were asked if they wished to provide the researcher with assumed names for all persons mentioned in the interview. These names were then substituted into all data concerning the subjects' experiences. Given the nature of qualitative studies, it was necessary that direct quotes from the interviews be used to demonstrate themes and to guarantee the validity of the information (Sandelowski, 1994). In substituting names at the discretion of the study subject, greater anonymity was achieved. However, most surrogates chose to allow the researcher to substitute the name of patients, family, doctors, cities, and hospitals. Moreover, no unrealistic promises were made to the subjects. For instance, if a participant asked the researcher to register a complaint about a specific health care team member with the hospital administration, the surrogate was informed that this was beyond the researcher's scope.

Other information provided within informed consent materials included an outline of how the study data was to be stored, and how materials would be destroyed at the end of the investigation. The study participants were assured that the study data would be kept securely in a locked file cabinet in a locked office area. Once the research study has been completed, destruction of the data, including transcripts, tape recordings, and other materials, will take place. Lastly, a confidentiality agreement was reached between the individual who provided transcription services and the researcher.

Sample Selection

Sample selection in GT is purposeful, as the intention behind the methodology is to "understand a particular group of individuals particularly well" (Crabtree & Miller, 1992, p. 39) and to glean descriptive and predictive information from the study

participants about the phenomenon under consideration (Straus & Corbin, 1998). Purposeful sampling entails the use of emerging theoretical themes within the study as a means to direct future sampling. As ideas and themes appear in the data, the researcher is given the freedom to select purposefully those persons who would provide the most relevant information to ensure the best possible representation of the phenomenon under investigation. This approach, also known as open sampling, allows the researcher to change direction in the selection of study subjects as the GT emerges from the data.

Strauss and Corbin (1998) outline several open sampling techniques. The researcher may purposefully select an area where data can be gathered in terms of "categories, their properties, and dimensions" (p. 208). A specific location, then, such an intensive care environment, would be an appropriate hospital environment for consideration in GT. Another method in open sampling relies on convenience because the researcher selects "the most readily available persons (or units) as participants in a study" (Polit & Hungler, 1999, p. 698). Many structural variations are possible when using convenience sample. One variation is to generate a list of predetermined persons to interview. Another variation involves the researcher waiting to determine who is available and willing to participate in the study. Convenience methods are used by most novice GT researchers. More complex methods of sample selection are typically undertaken by more experienced researchers (Strauss & Corbin, 1998).

When selecting an open sampling method, the researcher must consider what is ideal and what is practical. The particular resources available to the researcher, such as time and money, often inform the choice of one type of sampling over another. Open

sampling seeks the persons or data sources (such as books and records) that can best inform the research study (Strauss & Corbin, 1998). The combination of a specific site (i.e., an intensive care environment) and convenience sampling strategy (i.e., a listing of persons discharged as deceased) represented the best, most practical fit with the study question.

Since numerous study participants revealed dealings with only chronic illness, future sampling would need to include surrogates of patients with acute traumatic illness. The inclusion/exclusion criteria for the study eliminated expansion of the sampling because surrogates of trauma and pediatric patients were not included in the selection of potential participants.

The surrogates that came forward to participate in this study made decisions for patients with cancers, infections, and other mostly chronic or long term states of illness, as well as transplant recipients. Since most of the participants in the study asserted that the Catholic Church's Ethical and Religious Directives on decision making did not influence their choices, subsequent sampling should have included participants whose decisions were more informed by Catholic doctrine. Only one of the surrogates who came forward claimed Catholicism as her religious preference, and in this study, open sampling was constrained by the blind nature of the recruitment procedures. The researcher, in other words, did not know who had received initial letters of inquiry about the study and, as a result, was limited to interviewing only those surrogates who chose to respond.

DATA COLLECTION PROCEDURES

Case Identification

Gaining access to surrogates who underwent the process of deciding to withhold or withdraw life-sustaining measures for someone in an intensive care environment was accomplished in cooperation with a local Catholic hospital system. Every patient discharged from the hospital system is uniquely coded by the agency's mainframe computer, and disposition at the time of discharge is part of the code. Patients who are discharged to an extended care facility, for example, receive a different code than those who are discharged as deceased. A listing of all discharged patients was generated by the hospital system and analyzed by hospital staff to determine the site of the patients' service within the system.

The individual nursing managers who supervise the various intensive care environments reviewed a listing of all patients who died in their respective areas. Meetings were then held between the nursing managers and staff nurses who volunteered to send the recruitment letters. This meeting of the managers and the volunteer staff nurses took place periodically throughout the study to address any concerns or questions related to sending recruitment letters. The researcher also met with the managers and the staff nurses to check on the progress of the mailings.

The managers and staff nurses reviewed a computer-generated list of all patient discharges for the period of October through December 2003 and for the period of January through March 2004. This list provided a guide to the staff nurses as to the patients who had life-sustaining measures withheld or withdrawn prior to their discharge.

Patient medical records were then requested by the volunteer staff nurses for review of life-sustaining measures that were withheld and withdrawn. Life-sustaining measures included, but were not limited to, the removal of or refusal of artificial ventilation, artificial hydration and the devices necessary to deliver it, artificial nutrition and the devices necessary to delivery it, surgical interventions, cardiopulmonary resuscitation, medications to control heart rate or blood pressure, blood and blood products, hemodialysis, chemotherapeutic agents, and other medical interventions.

Withheld life-sustaining measures were identified by the staff nurses and managers through review of progress notes in the patient's medical record. Additionally, the patient's medical record was examined to determine if any health care team member made reference to one of the listed life-sustaining measures and whether or not it was ultimately withheld from the patient. This process ensured that any life-sustaining measures that were presented as a treatment option and then not initiated were later identified by the nursing staff responsible for sending recruitment letters.

Surrogates were identified through chart review of all patients who underwent withdrawing or withholding of life-sustaining measures in one of the intensive care environments. Once a potential study participant was identified, a letter was sent to the surrogate asking about the person's interest in participation in the study. All of the recruitment letters were sent by the volunteer staff nurses. The researcher provided the volunteer staff nurses with mailing materials such as envelopes, self addressed return envelopes, recruitment letters, and other study materials such as instructions for subjects replying to the research request.

In order to determine appropriate potential participants, volunteer staff nurses observed inclusion and exclusion criteria developed for this study. To be included in the study, a surrogate must have made a decision regarding the purposeful act of refusing consent for life-sustaining measures and/or must have made a decision regarding the purposeful act of removal of life-sustaining measures for an adult patient who received care while a patient in a the local Catholic intensive care environment. A surrogate was defined as legally designated or legislatively directed to act for a person incapable of participating in his or her own health care decisions. This distinction was specified in the Texas Health and Safety Code (Tex. Health & Safety Code Ann. §166.046, (Vernon, 1999)). Each surrogate was required to speak and read English, be at least 21 years of age and under 99 years of age, and must have had a prior relationship with the patient before making the decision to withhold and withdraw life-sustaining measures. Excluded from the study were those outside the inclusion criteria and also surrogates of pediatric and trauma patients, as it was felt that these surrogates' experiences were qualitatively different from those sampled. Additionally, the local Catholic hospital system's risk manager vetted the list of deceased patients for surrogates who had litigation or arbitration pending. Additionally, potential participants were excluded if less than 21 years of age or aged 99 and over. Potential participants who could not speak or read English and any person other than the person who was responsible for making the decision to withhold and withdraw life-sustaining measures were excluded. Any person who did not have a prior relationship with the patient prior to making the decision to withhold and withdraw life-sustaining measures was excluded.

It was estimated that 15-20 surrogates were needed to develop a theory to explain the process used to withhold and withdraw life-sustaining measures. This estimate was determined after examining similar previous research efforts, including that conducted by Swigart (1994), who studied 16 decision makers; Norton (1999), whose sample consisted of 20 surrogates; Hayes (2003), who worked with 13 surrogate decision makers; and Jacob (1998), who conducted research with 17 family members who engaged in decision making for incompetent intensive care patients. The current study was completed with a total of 17 surrogate participants, all of whom made the decision to withhold and withdraw life-sustaining measures for patients while they were in a Catholic intensive care environment.

Contacting the Potential Study Participant

All of the surrogates were contacted no sooner than three months and longer than one year after the death of the patient. Some surrogates chose to respond only after the first anniversary of the loved one's death. The one-year limit was chosen because the literature indicates that this period seems to be critical for remembering the events surrounding the death (Ringdal, Jordhøy, et al., 2001) and for creating a story (Walter, 1999) that the surrogate can live with and tell for the rest of his or her life.

The researcher requested a designated hospital employee to generate a computer listing of all deceased patients for the period beginning November 2003 and ending December 2003, and for the period of January 2004 through March 2004. A computer printout showing all deceased patients during these time periods was obtained and vetted by the hospital risk manager for cases that may have had legal or risk management issues

pending with the hospital. Volunteer staff nurses then reviewed patients' medical records for identification of patients who underwent withholding and withdrawing of life-sustaining measures. For accuracy, the names and addresses of surrogates of these identified patients were then compared and verified with the computer listing.

A two-part cover letter was sent to the surrogate listed in the patient's medical record (see Appendix C1 and C2). This two-part letter described the purpose of the study from the hospital and researcher's perspectives. The first part of the letter was signed by the managers of the intensive care environments. The second portion of the letter described the study's purpose and identified the researcher. This letter informed potential participants that no confidential information about themselves or their loved ones had been shared directly with the researcher and that participation in the project was solely at the participant's discretion. The researcher was thus blind as to which surrogates received letters, and the hospital system was blind as to which surrogates chose to respond to the research inquiry.

Using the names and addresses of the surrogates provided by the risk manager, two volunteer staff nurses from the intensive care environments sent the letters to the potential study participants. The letter inviting each individual to become a study participant detailed the risks and benefits of the study, as well as the right to decline to participate. All potential study participants received detailed information regarding how to respond to the study inquiry. The potential study participant was asked to reply to the researcher in one of three ways (see Appendix C2):

1. Direct telephone messaging: Potential study participants could leave voicemail

messages for the researcher with their name, phone number, and preferred time of day to be contacted. The researcher was then able to contact the potential study participants to discuss further their desire to be involved.

2. Internet e-mail: An e-mail address dedicated to the study allowed potential participants to send their contact information and questions electronically. The researcher was then able to contact potential participants to discuss their interest in the project.
3. Fill-in-the-blank card: A card with spaces provided for the surrogate's name, phone number, and signature attesting to an agreement to be contacted was included with the letter of inquiry. Potential participants could indicate on the card preferred times to be contacted to discuss the study. The cards could be mailed to the researcher via self-addressed, stamped envelopes included in the mailing packets.

When a potential study participant indicated a desire to be contacted, the researcher telephoned the individual at the stated preferred time. The researcher identified himself as a doctoral student at the University of Texas at Austin School of Nursing, and the potential study subject was informed about the study. Using an interview script (see Appendix D), the researcher described the study purpose and details to the potential participant.

Recruitment mailings were completed in two rounds. The first mailing consisted of deaths that occurred in the intensive care environments during the highest death months for the health care system. This mailing–for deaths during October, November,

and December 2003–yielded seven participants from 120 letters. The remaining 10 participants responded to the mailing for deaths occurring during the period of January, February and March 2004. This mailing consisted of 78 letters. A total of six letters were returned unopened to the health care agency and forwarded to the researcher. This occurred for a variety of reasons; most of the mail was returned due to incorrect addresses.

A total of 198 letters were mailed to potential participants. Of 21 individuals responding to the initial inquiry, 17 became study respondents. The mailings, therefore, netted a 4.22% response rate. Three potential participants chose to respond to the letter of inquiry via e-mail. Three surrogates chose to use the telephone to make initial contact with the researcher. Most of the surrogates responded by using the enclosed reply card and postage-paid envelope. The envelope was pre-addressed to the researcher's post office box, and the participants were instructed not to include any identifying information such as a return address on the envelope. Additional discussion of the recruitment process is included in Chapter 5 under the methodology heading.

Four potential subjects who ultimately did not participate in the study contacted the researcher to inquire about the project. Two of the surrogates declined to participate in the study after their conversation with the researcher. One of these surrogates cited concerns about confidentiality. His concerns were not related to the researcher or the study procedures, however. This surrogate made references to his work in government and did not want to risk his employer discovering the information that he might reveal in the study. Another of the potential surrogates was contacted and found to be appropriate

for inclusion in the investigation. However, he was suffering from his own health concerns at the time of the initial contact and did not respond to a subsequent phone call requesting his participation. A third potential participant inquired about the study but was found not to meet the inclusion criteria, because she was not a legally or legislatively designated surrogate. The fourth potential surrogate was not included in the study as his preliminary telephone information was virtually identical to a surrogate who had been interviewed the day before contact with the researcher. In keeping with grounded theory methodology, use of theoretical sampling allows the researcher to purposefully select participants that will add to the emergent themes. This fourth potential surrogate's information likely would not have revealed any new information and as saturation of the data was obtained. This potential participant was thanked for his interest but ultimately not included in the study.

Once a potential subject agreed that he or she would like to participate in the study, a mutually agreed upon time for a face-to-face meeting was established. During this meeting, the researcher and the study participant discussed the study fully, and informed consent was obtained. The study participants also agreed to devote time during this initial meeting to respond to interview questions and data collection requests.

Interviewing

Once informed consent was obtained and consent forms were signed, a short demographic form was completed by participants (see Appendix E). Demographic data included descriptors of both the surrogate and the patient for whom the surrogate made a decision. Study participants were queried about their relationship with the deceased,

about the surrogate's and the patient's religious affiliations (even if none), and about more traditional themes such as gender, age, and education level.

Upon completion of informed consent procedures and preliminary demographic data collection, the study participant was audio tape recorded in a face-to-face interview for approximately one hour. Holstein and Gubrium (1995) offer this conceptual advice about this active interview technique the researcher used: "It is the active interviewer's job to direct and harness the respondent's constructive storytelling to the research task at hand" (p.39) so the researcher will best elicit the desired information. Using the active interview technique allowed the researcher to shape the focus of the questioning as the interview unfolded and to probe for issues that best informed the research.

This strategy is in keeping with the theory behind GT, which calls for the researcher to change the questioning schedule as the study participant provides data. In this particular study, the constant comparison method required of GT allowed the researcher to develop probes that guided the questioning in appropriate and fruitful directions. In their discussion of how to question study participants, Strauss and Corbin (1998) encourage researchers to use the method that will best inform the developing theory. In this particular study, the active interview method allowed participants to inform the researcher of important themes, without the researcher imposing preconceived ideas about the type of information to be obtained (Holstein & Gubrium, 1995; Polit & Hungler, 1999).

The researcher initially developed a schedule of questions on his own, which guided the interview research during its beginning stages. An interview schedule is

included in the appendix (see Appendix D). This schedule called for the use of open-ended grand tour questions as a way of orienting the researcher to the participant and his or her experiences. Polit and Hungler (1999) define the grand tour question as "a broad question asked in an unstructured interview to gain a general overview of a phenomenon, on the basis of which more focused questions are subsequently asked" (p. 703). Grand tour questions were used to foster the study participant's perceived control over disclosure of the amount and type of information to be given in the research study.

As the theory emerged from the data provided by study participants, the interviews became more focused to include such prompts as, "Others who have been in your situation have found 'X.' Is this true for you?" Given the flexible and changing nature of the interview questions, the schedule presented here should be understood as an overview of the research probes and not an exact rendering of the wording used with each participant. Indeed, according to GT methodology, a fixed interview schedule cannot be codified. Changes must be made to the probes to respond to the study participants' education levels and varying degrees of comfort with personal disclosure.

DATA ANALYSIS

Grounded theory methodology can be used to examine the "sequences of action/interaction pertaining to a phenomenon as they evolve over time" (Strauss & Corbin, 1998, p. 123). This type of data analysis leads the researcher to develop a comprehensive conceptualization of the process under investigation. Data analysis followed the guidelines for reviewing grounded theory data as set forth by Strauss and Corbin (1998) and by Glaser and Strauss (1967).

All interviews were audio tape recorded and transcribed word for word using a standard word-processing program. Transcriptions were stored on compact disks and the researcher's computer. Field notes were recorded by the researcher as soon as possible after the interview. The data transcripts were read line-by-line by the researcher to identify significant words or phrases that might signal the emergence of important themes. These readings were conducted with an ordinary highlighter and a pen to record notes or questions about the data in the margins of the transcripts. Storage of the data, compilation of themes, and organization of the data was accomplished using Ethonograph Qualitative Data Analysis Software, version 5.07.

Use of grounded theory methodology requires the researcher to compare all data obtained, such as significant words and phrases, with all transcripts and to do so several times in an iterative manner. In this study, coding was completed in a sequential fashion, in that the researcher examined all newly transcribed interviews alongside all previously transcribed interviews. This comparison allowed for logical grouping and ordering of words and phrases (axial coding) to identify themes that were later linked to form the theory that expressed the phenomenon under consideration.

Comparison of the data prompted a change to the grand tour questions early on in the research process. It became apparent after the first few interviews that the initial grand tour question interfered with the surrogate's ability to tell crucial contextualizing stories concerning the deceased loved one. Surrogates expressed a need to inform the researcher about the patient before the last hospital stay; when provided with this opportunity, they communicated information that humanized the loved one. This

storytelling seemed to help surrogates make the transition from meeting a stranger (the researcher) to narrating a very intimate account of the decision-making process.

Initially, surrogates were asked about the process used to make the decision to withhold and withdraw life-sustaining measures from a loved one. For the surrogates, the word "process" seemed to be a foreign concept or a word which did not describe their way of thinking about the events surrounding the death of the loved ones. Subsequently, the interview question was revised so that surrogates were asked about the *steps* they used during decision-making. That term, however, was also regarded by the surrogates as inconsistent with their experience of the phenomenon under investigation. The question was revised a second time to ask the surrogate to imagine he or she had to write a letter to a friend who had to go through the same decision-making process. This question seemed to be the easiest for the surrogates to understand. Surrogates told the researcher about the kind of advice they might communicate to their fictitious friend, such as what to be sure to do or not do when making decisions for a loved one. Ultimately, however, the decision-making process was most clearly described by the surrogate's telling his or her story. Asking direct questions concerning the process did not illicit much in the way of structured, step-by-step narratives. Instead, the surrogates were able to communicate about decision-making through the telling of the events surrounding the last hospital stay for the patient.

Strauss and Corbin (1998) caution researchers to be aware of how changes in interview contexts or conditions can affect the interactions between researchers and participants. Revising the grand tour question did change the nature of the interaction

between surrogate and researcher in this study, in that it appeared to set each participant more at ease and to foster a more detailed accounting of his or her experience. The change did not seem to alter the essential structure of each of the surrogates' stories, however. Rather, participants provided more data and in a more expeditious manner after the change was instituted.

No sub-processes were identified during examination of the data for themes that could be linked together to express the process used by surrogate decision makers. Initially the researcher thought that the surrogates were articulating the presence of sub-processes. However, closer examination of the data revealed surrogates expressed similar themes in a variety of ways, and what appeared to be sub-processes were actually variant expressions of the major emergent themes.

BIAS CONTROL, STUDY RIGOR, TRUSTWORTHINESS

No research can be absolutely free of bias (Strauss & Corbin, 1998) because of the subjective nature of all qualitative study (Polit & Hungler, 1999). Some researchers argue that there is inherent bias in qualitative research, which makes it incumbent upon the investigator to identify his or her preconceptions and to invite detailed scrutiny of the research process. Critical scrutiny and an adequate audit of the project should take place concurrently with the study (Strauss & Corbin, 1998). These tasks can be accomplished by recruiting an outside expert to review (a) the written data transcripts; (b) copies of the iterative coding of the data; (c) field notes related to the data, which may include notations about the study participants, such as their dress and mannerisms, the environment in which the interview took place, the researcher’s thoughts about the

participant, and coding decisions about the data; (d) the processes used in creating the themes for theory development. The individual conducting such a review should be expert in methodology or content or both (Strauss & Corbin, 1998). The use of such an outside expert can elucidate bias and add to a greater sense of the data's trustworthiness. Review of annotated notes and the original data transcripts can validate or, in some cases, controvert the researcher's representation of the data. As this particular study has been guided by the expertise of a dissertation committee, it can be argued that five experts are reviewing the researcher's work and are thinking and reasoning about the results. Each dissertation committee member has experience with qualitative methodologies and has subjected the project to detailed scrutiny. This element of the study adds to its trustworthiness.

Study subjects, through a process called "member checking," can also be asked to review an investigation's results in order to add to the "truthfulness, consistency and transferability of qualitative research" (Slavin & Sines, 1999, p 80). Member checking was used in the current study to ensure the trustworthiness of the results. Fourteen letters were mailed to the surrogates to obtain feedback concerning the researcher's interpretation of the study results. Each of these surrogates had asked to be informed of the study results. The researcher used the surrogates' request for study outcome as a means to ask if the participants would provide feedback about the results. One surrogate responded to the inquiry for feedback. Surrogate 5 offered this statement about the study results: "It is difficult to believe that this issue can be brought together by such a 'simple' model; but it is true."

Glaser and Strauss (1967) called attention to the issue of credibility in GT research by remarking that an investigator conducting such an effort often "faces the problems of conveying to colleagues and laymen the credibility of his [or her] discovered theory so that they can make some sensible judgment about it" (p. 228). Since the development of the GT methodology, researchers have been looking for ways to lend credibility to their results. Glaser and Strauss direct the researcher to communicate the study results in a manner so that the reader mentally "sees" the experience of the participant. Written expression of the theory produced from the study results can also be complimented by the production of a visual model (Walker & Avant, 2005). A model representing the theory derived from the current study's results is presented in Chapter 4 (see figure 4.2).

THE RESEARCHER'S INFLUENCE UPON THE PROPOSED RESEARCH

Qualitative investigation has its roots in the philosophical traditions developed by thinkers, such as Husserl and Dilthey, who were interested in learning about the individual's "lived-experience" or "life-world." Influenced by the writings of these philosophers, Martin Heidegger extended qualitative methodology into the interpretation of *dasein*, a German word for "being there." Heidegger is recognized as the developer of the hermeneutic circle, in which the investigator is a natural part of the research and cannot be separated from the data that emerges (Guignon, 1993). Another image that captures the drama of contemporary qualitative research is the Circle of Shiva, the androgynous Hindu Lord of the Dance and of Death. In this image, "a constructivist inquirer enters an interpretive circle and must be faithful to the performance or subject,

must be both apart from and part of the dance, and must always be rooted to the context" (Crabtree & Miller, 1992, p.10). The idea here is that qualitative investigation allows for continual discovery of a phenomenon followed by interpretation from the standpoint of the researcher and the participants.

Research does not take place independently of the researcher's background. In many instances, it is the researcher's experiences that provide the source for the investigation (Strauss & Corbin, 1998). Creswell (1994) encourages the qualitative researcher to be fully forthcoming in his or her experiences "that provide [the reader] familiarity with the topic, the setting or the informants. These experiences likely will shape the interpretation of the report" (p. 147). Disclosure of the researcher's biases and prior experiences may help to inform criticisms of the research description and details. This disclosure may also help the reader of the research findings to understand the reasons for specifics of the work in the research report. This researcher's biases have been disclosed to the reader in the following paragraphs and Chapter 4. This researcher's extensive clinical experience has influenced the selection of GT as the most appropriate research method for the proposed research. The often stressful environment of intensive care and the critical nature of the decisions to be made in such units have led the researcher to believe that surrogates may share a common experience. It should be noted that this researcher had experience in the area of palliative care nursing in the institutions where the data was collected. It is through this experience that the researcher first began to consider that there might be some sort of common process that surrogates undergo to make a decision to withhold and withdraw life-sustaining measures in an intensive care

environment, and that the process may involve stages. The researcher's inspiration to develop the proposed study came from watching the day-to-day struggle of surrogates placed into decision-making situations and watching nurses ill-prepared to support these persons. Hence, the use of GT is consistent with the study of the process used by surrogate decision makers to withhold or withdraw life-sustaining measures.

It should also be noted that the researcher was raised within the Catholic faith, attended Catholic elementary schools, and his professional work has been in a Catholic hospital setting over the five-year period preceding the proposed study. Additionally, the researcher continued a voluntary relationship with this same hospital system as the committee chair for the governance of the ethics process.

These personal biases should not diminish the power of the results gleaned from the research. Instead, the reader is asked to understand that the researcher’s background has informed his formulation of the study. It should be seen that dasein, or being there, has provided the researcher with a unique perspective on the world of surrogate decision makers. This perspective has allowed for the envisioning of a more focused and useful study.

SUMMARY

This chapter has presented a discussion of the methodological issues associated with GT as a method for the investigation of surrogate decision makers who decided to withhold and withdraw life-sustaining measures in a Catholic intensive care environment. An argument was made that GT represents the most appropriate research methodology for the question under investigation in the current study. Since little research concerning the

phenomenon of surrogate decision making has been formally reported, a methodology that both identifies and investigates process questions is particularly suitable. GT meets this criterion and, moreover, has been utilized previously to explore the issues associated with this area of investigation, namely end of life decision making.

CHAPTER 4

PRESENTATION, ANALYSIS, AND INTERPRETATION OF FINDINGS

The purpose of this study was to describe the process used by surrogate decision makers who decided to withhold and withdraw life-sustaining measures in a Catholic intensive care environment. The researcher has produced a grounded theory model of the surrogates' process. This chapter will explain that process and represent it using a visual model. The development of the model was accomplished through the face-to-face interviews with 17 surrogates who had made a decision to withhold and withdraw life-sustaining measures for an incompetent patient while that person was in a Catholic intensive care environment. The data revealed a series of steps that surrogates completed in their efforts to make decisions on behalf of patients who were not competent to participate in their own health care. This chapter will explain the surrogates' decision-making process through the use of quotes and thematic interpretation.

Discreet themes came forward from the data, and the themes were naturally clustered into groups represented as domains. The term *domain* is defined as "a sphere of knowledge, influence, or activity, the set of elements to which a mathematical or logical variable is limited; *specifically*: the set on which a function is defined." (Merriam-Webster Online Dictionary, 2005). The clustering of themes into the domains represents a set of functions in the process of decision-making which influenced the surrogates' decisions regarding the withholding and withdrawing of life-sustaining measures for an incompetent patient while that patient was in a Catholic intensive care environment.

Review of Terms

For the purposes of this study, a surrogate was defined as a person who was 21 years of age or older, and who was legally designated as a medical decision maker for another individual who was incompetent to make his or her own decisions. Life-sustaining measures included medical technological equipment, procedures, devices, processes, modalities and other interventions known by medical science to be life-sustaining or prolonging. Some examples of life-sustaining measures considered by surrogates interviewed for the study were artificial ventilation, artificial hydration and the devices necessary to deliver it, artificial nutrition and the devices necessary to deliver it, medications to control heart rate or blood pressure, blood and blood products, cardiopulmonary resuscitation, surgical interventions, hemodialysis, and chemotherapeutic agents. Withholding of life-sustaining measures was defined as the purposeful act of refusing consent for life-sustaining measures. Withdrawing of life-sustaining measures referred to the actual removal of life-sustaining measures. A Catholic intensive care environment was defined as an intensive care environment influenced in policy, practice, or both by the most recent edition of the Ethical and Religious Directives for Catholic Health Care Services (United States Conference of Catholic Bishops, 2001). An intensive care environment was defined as

> a specially staffed, specialty equipped, separate section of a hospital dedicated to the observation, care, and treatment of patients with life threatening illnesses, injuries, or complications from which recovery is possible [and that provides] special expertise and facilities for the support of vital function and utilizes the

skill of medical nursing and other staff experienced in the management of these problems. (Bajan, 2003, ¶ 5)

The Surrogates and the Interviews

According to the study inclusion criteria, 17 surrogates who responded to the letter of inquiry for research participation were appropriate for the study. All of the surrogates were related to the patient for whom they made a decision to withhold and withdraw life-sustaining measures. These relationships were significant relationships such as adult child, spouse, and sibling. Veatch (1984) would refer to these surrogates as "bonded guardians" inasmuch as all of the surrogates indicated the existence of an ongoing and amicable relationship with the person for whom they made a decision.

Detailed profiles of individual participants are not presented here, due to the sensitive nature of the information and the need to protect the surrogates' privacy. Because many of these surrogates may continue to receive health care from the Catholic hospital system, and several of the included comments may not reflect well on health care team members, it was critical that the researcher not disclose information that would lead to identification of the surrogates who participated in this study. Where appropriate, pseudonyms were used to obscure the identities of surrogates, family, and health care providers. Likewise, if surrogates' transcripts might have included identifying information, such quotes were excluded from this report.

A complete picture of the surrogates and the patients for whom they made decision to withhold and withdraw life-sustaining measures is presented in Table 4.1. Most of the surrogates were female (n= 12) and there was a split between spouses (n=10)

and adult children of ailing parents (n=6). Only one sibling participated; however, this may in part be due to the fact that siblings fall later in the designated order of decision makers, according to the current Texas law (Texas Academy of Palliative Medicine , 2003;. Tex. Health & Safety Code Ann. §166.046, (Vernon, 1999)).

Table 4.1

Demographics of the Study Sample

	SURROGATE	PATIENT
SURROGATE'S RELATIONSHIP TO THE PATIENT		
Wife	6	n/a
Husband	4	n/a
Sister	1	n/a
Son	1	n/a
Daughter	5	n/a
total	**17**	n/a
AGE		
21-30	1	
31-40	2	2
41-50	4	1
51-60	3	3
61-70	3	2
71-80	4	4
81-90		4
91-99		1
total	**17**	**17**
GENDER		
Male	5	8
Female	12	9
total	**17**	**17**
ETHNICITY		
African American	2	2
White	13	13
Hispanic	2	2
total	**17**	**17**

	SURROGATE	PATIENT
HIGHEST LEVEL OF EDUCATION COMPLETED		
Grade School		1
High School (GED)	3	7
Some College	6	2
College Degree	5	5
Masters Degree	3	1
Doctoral Degree		1
total	**17**	**17**
RELIGIOUS PREFERENCE		
Christian	3	1
Episcopalian	1	1
Baptist	4	6
Lutheran	1	2
Full Gospel	1	
Methodist	4	3
Deist	1	
Agnostic		1
Catholic	1	2
Protestant	1	1
total	**17**	**17**
CHURCH ATTENDANCE		
2-3 times per week	4	6
Once a week	7	5
None	1	4
Special Occasions or Holy Days	2	2
Other	3	
total	**17**	**17**

The age range of surrogates was from 23-82 years. The patients ranged in age from 42-93 years. Few non-white surrogates participated (n=4), with two surrogates claiming Hispanic origin and two surrogates claiming African-American status. Surrogates' ethnicity categories matched the ethnicity categories of the patients. Most surrogates were well educated (n=14) with some college or a college or masters degree.

The educational background for patients was split with 8 having a high school diploma or grade school only. All other patients had some college or a college or masters degree. One patient had a doctoral degree.

Religious preference was represented by mostly Christian faiths (n= 15) with Baptist (n=4), Methodist (n= 4), Christian/Protestant/Full Gospel (n=5), Episcopalian (n=1), and Lutheran (n=1) representing the religious preference for these 15 surrogates. One surrogate claimed Deist as his religious preference. One of the surrogates and two of the patients claimed to be Catholic. None of the surrogates and none of the patients attended religious services daily. Eleven of the surrogates attended religious services once a week or more, and 11 of the patients attended with the same frequency. Four of the patients and only one of the surrogates did not attend religious services at all. Two of the surrogates and two of the patients attended religious services on special occasions or holy days. Three of the surrogates claimed "other" as the category describing his or her attendance at church services. These three surrogates explained they attended services infrequently but not necessarily on religious occasions or holy days.

Surrogate participants were interviewed in the place and at the time of their choice and were asked to describe their decision-making experiences. The length of the interviews ranged from approximately 35 minutes to over 90 minutes. The amount of detail provided by each participant varied greatly. All of the patients for whom the surrogates made a decision to forgo life-sustaining measures died shortly after the surrogates communicated their desires to withhold and withdraw those life-sustaining measures. Once the health care team enacted the surrogate's decision, the patient died

within a range of minutes to several hours after cessation of life-sustaining measures. Only one of the patients survived several days following the withholding and withdrawing of life-sustaining measures. The decisions primarily revolved around the removal of intubation and cessation of ventilation for the patient. Other treatment decisions included forgoing surgery, cardiopulmonary resuscitation, or hemodialysis.

Surrogates who had a brief experience with the intensive care environment gave shorter interviews while longer interviews occurred with individuals who made decisions on behalf of patients who spent more time in the hospital. The longest recording interview time resulted from the story of a woman whose husband was in intensive care twice during a three-month period of ongoing hospitalization. Two of the surrogates' stories were relatively short, approximately 35 minutes. One involved a man who made the decision to remove a ventilator following his wife's massive coronary event, while the other concerned a woman who elected to forgo CPR for her husband, who was in the end stages of liver cirrhosis.

All of the surrogates expressed a need to tell the researcher about the patient. Specifically, surrogates universally described the deceased in terms of his or her relationship to the surrogate, for instance as a parent, spouse, or sibling. The surrogates also described the patients as unique people. For example, surrogates made comments like, "He was a great practical joker," or "He was an alcoholic," or "She was a good church member." Personal, historical context seemed to represent a crucial element of the story that the surrogates told. The surrogate could not speak about the patient without

telling the researcher who the person was before illness and before the time in which the surrogate had to act on the patient's behalf.

All of the surrogates described the events leading up to and including the actual decision to withhold and withdraw in a linear format. After telling the researcher about the patient, the surrogate would then tell the story of the disease or of the events leading up to the final hospitalization for the patient. The story might have taken place over the course of several years, such as found in patients with cancer, or within just a few hours, such as was the case with patients who experienced acute events like cerebral vascular accidents or cardiac arrests.

Most of the surrogates expressed a desire to help others who may one day be in a similar decision-making situation. The surrogates stated that they hoped sharing their experience with the researcher might further this goal. This was made particularly evident by the number of surrogates who requested information from the study results. In each case, the surrogates reported that they wanted to ensure that the model derived from the study was rendered in a format that could be useful to surrogates as well as health care providers.

Bias is inherent in grounded theory research (Denzin & Lincoln, 1998), and the research findings that emerge from such efforts will always be subject to critique. The most basic question that arises when grounded theory research is conducted is whether the ideas the researcher "discovers" truly capture the sentiments of the subjects. For instance, what subjects say often is just as important as what is not said (Denzin & Lincoln, 1998). A researcher's feminist or Marxist biases, for example, may cause him or

her to impute qualities and meanings to interview data that subjects may not have fully articulated. It is the researcher's responsibility to assure that what is eventually published in textual format accurately and realistically portrays the views of the research informants (Denzin & Lincoln, 1998).

It is my intent to represent accurately the voice of the surrogates who made a decision to withhold and withdraw life-sustaining measures in a Catholic intensive care environment. However, certain of my own biases must be disclosed to assure that the reader of the results will be able to screen for any undue prejudices toward the material.

Disclosure of Researcher Bias

My experience with end-of-life issues started when I graduated from nursing school in 1981. One of my first patients was a young man with AIDS, which at the time health care providers at the time referred to as Gay-Related Immunodeficiency Disease (GRID) or Gay Cancer. Working the night shift, I entered this patient's isolation room (all GRID patients were isolated in laminar flow rooms at that time) dressed in personal protective equipment. I introduced myself, as I do with every patient, by reaching forward and touching the patient's arm. At my touch, he began to weep. As a new graduate, I instantly assumed that I was somehow at fault for this outburst. The patient, however, related to me that he was crying because I was the first person to have touched him in over 12 hours. This explained the stacked meal trays and the empty water pitcher I had seen in the vestibule before entering his room.

The patient told me that his family would have nothing to do with him, even though it was clear he was dying, and that the health care team was frightened of his

disease. Not one person had been in his room in over 12 hours. Outraged though I was, I hid my contempt for his estranged family and the prejudices being shown by my fellow workers. I did my best to care for this young man who died the next day. Unfortunately, he died alone, frightened and in pain.

This moment forever changed me and how I viewed death and dying in a health care environment. I focused my care on those with HIV and AIDS, and I watched many people die between 1981 and the mid-1990s, before drug therapy became a viable form of treatment. Oncology nurses taught me a great deal about pain and symptom management, as many AIDS patients were cared for in oncology units.

Death and dying has always been a part of my nursing career. Over the years, I have cared for many people with many different types of terminal illness, including cancer. Most recently, I was employed in hospital-based palliative care. This is where I began to see surrogate decision makers struggling with issues, and I was particularly struck by the effort it took them to make sense of the health care system at perhaps the most stressful time of their lives. I would spend at least an hour on most new palliative care consults, attempting to find a language to discuss the patients' conditions that made sense to surrogates and their families. I would later visit these very distressed people over and over to explain and answer questions about complicated medical interventions. Often, I would help the surrogate to weigh the burden and benefits of modalities and treatments.

It was very clear to me that there were similarities among the decision-making processes surrogates were using, and that most health care providers were unaware of the

way in which this decision making followed a relatively consistent pattern. It occurred to me that if we knew more about the processes being used by surrogates as they made decisions to withhold and withdraw life-sustaining measures, then we in the health care professions could better facilitate meaningful discussions regarding end-of-life care. This is not to say that health care professionals would be in a position to unduly influence surrogates, but instead they would become more capable of assisting surrogates in an informed manner as they make their decisions. This line of thinking prompted me to investigate the process of surrogate decision making regarding withholding and withdrawing of life-sustaining measures.

It should also be noted that not only did I grow up in a Catholic household and attend Catholic schools from grades 1-6, I have also worked in a Catholic health care institution and served on that institution's ethics committee. I feel that the Ethical and Religious Directive for Catholic Health Care Services (ERD) (United States Conference of Catholic Bishops, 2001) has provided me with a sense of structure and direction regarding end-of-life care that I did not sense in other secular institutions. I agree with the ERD (United States Conference of Catholic Bishops, 2001) that the faithful are not required to take extraordinary means to preserve biological existence at all costs (e.g. personal, spiritual, and financial costs). I also agree with the ERD that surrogates have the right to make informed decisions for incompetent patients, particularly when patients' wishes concerning the end of life are known by surrogates. I believe, furthermore, that sanctity of life should be respected; however, I do not think a person should be required to endure excessively burdensome treatments for an unknown potential benefit.

Finally, I have written about the tendency of health care providers to use language that is connotatively meaningless to surrogates, and I feel that it is a health care professional's responsibility to avoid this and instead to use appropriate language when obtaining informed consent for burdensome treatments (Limerick, 2002). Communication skills are most often deficient in health care when it comes to explaining complicated and complex medical interventions to those who must make decisions for others. However, I am convinced that health care professionals should overcome this and be actively involved in the decision-making process with surrogates.

Remembering the Patient as a Prelude to the Interview

All of the surrogates began speaking about their loved ones prior to the tape recording of the study interview. So important was it to surrogates to provide this contextual information that the researcher changed the grand tour question. Instead of asking surrogates to talk about the last time the patient was admitted to the hospital, the researcher began the interviews by requesting that the surrogate tell the researcher about the patient. If prompts were needed, the researcher asked the surrogate to relate anything that the surrogate felt was important about the loved one.

Each of the surrogates told a story about the patient that provided the researcher with a picture of who the patient was before she or he became ill and died. These stories were usually about the relationship of the patient to the surrogate, about the patient's profession or some combination of both. Perhaps the most emphatic of these statements came from Surrogate 1:

Well, I just wanted to tell you who we are, who he was—a teacher, a father, a husband. And, loved by us all, of course. He loved his job, he loved to be there. He was a great teacher—loved by all the students. And then I wanted to tell you about his illness. Should I do that?

Similarly, Surrogate 10 made this comment about her sibling:

My sister Betty, it was three daughters. And Betty was the old[est] daughter. And Betty was a very sweet person. She always worked to help people. She was a people person. And, um…I don't know. She's missed a lot. And I think there's not a day go by that I don't think of Betty.

Surrogate 6 talked about the patient's lineage, including the coincidental resemblance of this death to prior deaths in the family. She seemed to take comfort from such information:

He was 81. He was a very vibrant man. Had a pacemaker. Was in constant checkups with the cardiologist. And he and my mom had been married 57 years. Had one brother. And he had four grandchildren. At the time, two great grandchildren. Actually three great grandchildren. And my son's wife was pregnant at the time of his death. So it was kind of neat that I was able to have her afterwards. And that had helped me with my grief because I was pregnant when my mother's father died. So that helped my dad through the grieving process. So it was kind of eerie. It was really kind of eerie that this happened to me like it happened to him.

These efforts to contextualize represented more than introductory comments to the researcher. They appeared to help the surrogate remember the patient as a person and not as the object of a research study. Each patient was a unique individual characterized by the surrogate as someone special in that surrogate's life. Each surrogate emphasized the value and importance of that patient upon the lives of the surrogates and others in the community and family. The message that all of these patients were clearly loved by the surrogate and family came through these contextual settings. While not part of the thematic summary, this information represents a key element in introducing the research questions and obtaining data from the surrogates.

THEMATIC SUMMARY

Surrogates shared diverse experiences related to withholding and withdrawing life-sustaining measures for loved ones while in Catholic intensive care environments. Because stories change over time, the stories may not reflect the actual events as they happened. Rather, these accounts represent how the surrogate remembers the events and the person's own unique experience related to the process of decision making for a terminally ill loved one while in an intensive care environment. No presumptions of good versus bad or right versus wrong are made in this chapter.

Thematic analysis of the 17 stories produced a total of nine themes. These themes were then clustered into areas or domains representing the decision-making process. The process used by surrogates deciding whether to withhold and withdraw life-sustaining measures in a Catholic intensive care environment consisted of a personal domain, an intensive care environment domain, and a decision domain. While these domains are

presented as separate entities, it should be noted that many parts of the decision-making process were interconnected and were at times related to another domain or theme. Moreover, the surrogate's course of decision making was an iterative process, with the surrogate repeatedly moving back and forth between the domains. However, once the surrogate came to the realization that continued life-sustaining measures for the patient was futile, a series of interrelated events quickly ensued. This part of the process was expressed by surrogates as two separate, yet connected steps within the process and as a consistent end point for the personal domain and the intensive care environment domain. Surrogates expressed that this part of the process resulted in realization of the futility of continued life-sustaining measures for the patient and moved them into the decision domain.

All of the surrogates engaged in some actions represented in the process model, and none demonstrated a different decision-making process than the one described. Each of the themes that comprise the model is represented by one or more excerpts from the transcripts of the surrogates' interviews. Where appropriate, names of persons or places have been changed to protect the surrogate's privacy. Individual demographics are not included, so as to further obscure surrogates' identities. The following is a discussion of the domains and themes. The grounded theory is then presented showing the integration of the domains and themes.

PERSONAL DOMAIN

The term *personal domain* refers to the processes that surrogates used to engage members of the surrogate's family and used to engage in self reflection. These two processes were intertwined and eventually led to the decision to withhold and withdraw life-sustaining measures. For most surrogates, decisions regarding withholding and withdrawing life-sustaining measures were made in the presence of family members. Surrogates described their connections to family in a variety of ways. Family members were present either before, during, or after decision-making processes had been completed. Surrogates rallied their families around them, either in person or virtually, such as by telephone. Surrogates' families seemed to be important to all surrogates, even if the families were not present at the actual time of decision making. Surrogates whose families were not present telephoned family members to inform them of their decisions or to obtain agreement about the withholding and withdrawing of life-sustaining measures. In all cases, surrogates sought health care information so as to share it with their families, whether or not the family members were physically present. This family discussion ultimately led surrogates to recognize the futile nature of continued life-sustaining measures and to authorize the withholding and withdrawing of life-sustaining measures.

Rallying Family Support

Rallying family support involved the surrogate's need to expend effort to get family members to the hospital for support, discussion, and assistance. Family could be blood relatives of the surrogate's or patient's family by birth or marriage such as parents, spouses, children, siblings, or in-laws. Additionally, family may have included other

individuals who were not related to the patient or surrogate such as a church member, clergy, close friends, and even members of other families in the intensive care waiting environment. Surrogates sought opinions from and engaged in discussions or information sharing with family members. Ultimately, the surrogate obtained agreement with family members about the course of action for the loved one in intensive care.

All of the surrogates spoke about their efforts to get family to the hospital for support and discussion about the patient. This effort generally took place as soon as the surrogate knew that the patient had been admitted to the hospital and occurred irrespective of the patient's ability to communicate. The presence of family helped each of the surrogates with the decision-making process and prevented family disagreements. Opinions were obtained from the surrogate's family members, and help was given to the surrogate to remember what the patient might have wanted in terms of life-prolonging measures. While all of the surrogates made the final decision regarding withholding and withdrawing life support, family involvement was important to them as they engaged the decision-making process. Surrogate 4 stated, for example, "Well, in the meantime my husband got to the hospital and my sister got to the hospital, and they all were able to see her [the patient] and they took her off [to surgery]."

Family support was not necessarily limited to a few people or to individuals who were part of the immediate family. Surrogate 10 commented:

> I had a house full of company. And we all went outside and was talking and my cell phone went off. And it was the hospital. And then I just kind of, I think I broke down, and everybody was saying, "What's wrong?" I said it's the hospital.

> They said get there soon in intensive care…So my son and us… And he come out…So he and some of my cousins drove me up here. So I went along. And like I said, later, other family members that was down for Christmas came up to the hospital. And my pastor and his wife came. We just stayed there. I mean everybody just took turns going in and out talking to Betty, you know. Just talking to her.

Often, the events leading up to the last hospitalization were unexpected by the surrogate, who could not always be present with the patient at the time of the hospitalization. Surrogate 6 asserted that if the surrogate could not be immediately available to join the patient at the hospital, use of a family member as substitution for the surrogate was acceptable. When the surrogate could not immediately be with the dying loved one, the surrogate chose a practical solution. Surrogates asked family members to join the patient at the hospital to be the surrogate's surrogate. Surrogate 6 had this to say:

> My son was the first to be there because I had to go get mom. So I drove to [name of town] and picked up Mom. So that was probably the hardest time, wanting to be with Dad. And that's why I sent my son. And big support group, actually my ex-husband's wife, Connie. She's like family. So I called Connie, too. So Connie met Dad… …So she and my son met Daddy with STARFlight. Because my husband …it was hard for him to leave immediately…So I went to pick Mom up; Mother and I went to the hospital.

This surrogate also presented an example of the kind of networking that takes place within the family, both in person and by phone. It was important to this surrogate,

as well as others interviewed, that family be present when bad news was delivered: Surrogate 6 had this to say:

> And the doctor came in and by that time… by that time my husband was there, it was still Connie, Bill, and Connor, my other son. And my brother unfortunately was in Oklahoma at the time, and his wife. And he was driving home as fast as he could, and my son kept him up via cell phone of what was going on. But we told him it wasn't good; so we were preparing him.

Surrogate 2's comments demonstrated that assistance during the decision-making process with people not related by blood or marriage to the surrogate or patient could be effective support for the surrogate: "Primarily I have a huge support system. We both did. My husband and I both did. Friends from our church. Just people. They're like our family, because we don't have any family here."

Each of the surrogates relied on family members to give them input whether for or against the surrogate's decision to withhold and withdraw life-sustaining measures. Most of the surrogates discussed the decision to withhold and withdraw life-sustaining measures with one or more members of their family even if that member was the patient. Surrogate 1 gave the best account of this family discussion:

> As far as actually a process like, how I decided that, I talked to my daughters; I said, "Look." Of course if any one of them had said, "No, don't do this," we would not have done that. We all had to agree that this is the thing that we should do. I talked to Dr. [X], told them what he had said, and what Dr. [X] said. Then we decided…we would never have done it if one of those girls had disagreed.

Never. That's me and my three daughters, and I have a wonderful son-in-law. He didn't voice his opinion. He was just always there to support me.

An example of acrimonious input from family members is best seen concerning Surrogate 8. Even though the surrogate and his sister would, according to the Texas Health and Safety Code (Tex. Health & Safety Code Ann. §166.046, (Vernon, 1999)), act as the official decision makers, the surrogate said he spent time speaking to his family about who should make the final end-of-life decision on behalf of the patient:

> … We need to know what to do if like, if they pull the plug or don't pull the plug. Somebody needs to have the authority to tell them [the health care team]. So what do you think? And I think they [other family members] had talked about it before I was there because one of the aunts says, "Well, Sam says, 'I think Tim is too young.'" And another [aunt] says, "Well, Sam and I think it should be him [Sam]." And I was just like, I've never met this guy [Sam, an uncle] before. And this is my dad, like in my head. And I just like open my eyes, and the other one [aunt] is like, "Well that sounds good to me. Let's do that [appoint Sam as decision maker]." And they all turn like simultaneously and walk like two steps. And I'm like, "Hey, I don't think so." And they turn around and look at me kind of angrily. And I'm like, "It's my dad. I'm old enough to, you know, to make the decision. And I'm going to be the one making the decision."

Surrogate 4's statements highlight the influence of the patient upon the surrogate and upon the process of obtaining family agreement. This surrogate spoke of the family's communication with the patient prior to the time in which a decision regarding life-

prolonging measures needed to be made. It is apparent that, even though this communication had occurred, the family still needed to come to a consensus about whether or not to stop cardiac defibrillation:

> We all, as a family, agreed not to continue putting her through that [defibrillation]. And that decision for us was easy because my mother was very, very clear with what her wishes were in the event that anything were to happen. There was no will [referring to medical power of attorney], there was no instructions, nothing, other than her conversation with us.

This surrogate stated that it was important for family to be present and to be a part of the process. This surrogate used her memories of her mother's conversations with other family members to come to consensus with her family about withholding and withdrawing life-sustaining measures. She then instructed the physicians to stop life-sustaining measures.

Surrogate 2 stressed the need for family to be present after a decision has been made to forgo life-sustaining measures. This surrogate told the story of her family's presence at the death of her husband: "So the whole family, our immediate family, was there, and we had probably had about 12 or 15 people in the room. We just had a… It was a beautiful experience as deaths go." The family's being a part of the death process helped the surrogate to know that the family agreed with her decision to withhold and withdraw life-sustaining measures.

Finally, Surrogate 7's comments highlight the importance of rallying family members, even when they cannot be present at the time of the decision. The following

provides details about how Surrogate 7 communicated with her family after her mother's death:

> I only had one sister, and she died about 15 years ago. So I was the only one left. My husband was working out of the country. I mean, it would have been nice if my daughter had been there, but she had a baby. You can't drag a baby up there…It would have been nice if one of my nephews had been there. But that's all. I'm very, very close to him…I didn't know where my nephew was. And then I talked to her [patient's] only living sister. She was the first one that I called, and she asked me, you know, what was wrong. And I said, "Well, the doctor said that mother had a dead bowel." She said, "Yeah, that runs in our family." I said, "Well, nobody told me"…and then she went on to tell me some things. I said, "I didn't know that."

The opinions of family members and other individuals were used by surrogates to help them make decisions about whether to withhold and withdraw life-sustaining measures. It was important to surrogates that the advice they sought come from individuals who had been through a similar decision-making process for someone in the past. Surrogate 10 spoke, for instance, about the need to hear from her mother while making treatment decisions for her sister: "Well, there's one thing that she [surrogate's mother] said: 'I definitely don't want her to go through is all of the different machines, life support, and the shock part that they do with the heart.'"

Another surrogate sought the advice from family members who were unrelated to either the surrogate or the patient. Surrogate 2 solicited the advice of the patient's closest

friends, even though the surrogate and her husband (who was the patient) had had many conversations related to end-of-life care and treatment decisions:

> His two best friends…Well, initially when we first got back here to Austin…the two best friends out of the people that I knew my husband trusts the most. And I felt they knew his wishes. I mean, he knew that I would respect his wishes, but I knew these two people would perhaps know things I didn't know, or see a different perspective perhaps I wouldn't see. There were two people that he more or less asked to…you know, help. And this went back to the transplant days. These two people he asked to do specific things for him if he were to die. And so I knew that he trusted them like he would trust his brother. More than his brother [laugh], since his brother wasn't named among those people.

Not all surrogates felt the need to seek others' opinions outside of their immediate families. In speaking about the decision to withhold and withdraw life-sustaining measures from her father, Surrogate 6 had this to offer:

> We made the decision on our own…and we didn't even make it with our minister. Just our family made the decision. No opinions. It was just immediate family. We made that decision on our own. But that's after we assessed the medical. We had such strong faith; we didn't need the minister there at all. He was there to help be a supporter before and after, but not during. I didn't feel he needed to be included in that decision-making process.

For the surrogates in this study, seeking others' opinions, especially from outside of one's family or from close loved ones, may not necessarily play a role in the decision to withhold and withdraw life-sustaining measures.

Surrogate 1 provided a detailed account of this part of family rallying:

> Well… it's interesting [being in the ICU waiting room]. I mean, it could be interesting if you didn't have somebody so sick. You get to know a lot of people. People bond because you know about their families. You see those people go in and come back…When I was sleeping out there, I would get up and make the coffee for ICU, then go in there at 6:00 to see him [the patient].

Surrogate 6 also talked about bonding with others in the ICU waiting area: "Everybody in the intensive care unit was supportive of everybody else. We were all there together. No, just…yeah, other families, strangers. Everybody was very nice." However, this surrogate made no mention of eliciting support from these other families in the intensive care waiting area.

Evaluating Patient's Past and Present Condition and Preferences

Evaluating the patient's condition and preferences was done from the surrogate's understanding of the information being received and the surrogate's perception about treatment deemed to be physically, emotionally, or psychologically burdensome. In this thematic presentation, surrogates needed to know that the patient had received every chance to reverse the condition through the technology available in an intensive care environment. Surrogates often had preconceived ideas about what limits that they might place on medical treatment for a loved one, and occasionally a surrogate and the loved

one already had developed a plan for end-of-life care. Eventually, surrogates came to a realization that the patient's potential quality of life was not in keeping with the surrogate's and patient's values.

Integral to the surrogate's decision-making process regarding the withholding and withdrawing of life-sustaining measures was the surrogate's need to understand the complexities of the patient's physical condition and progress compared to arrest of the disease process. Evaluating the patient's condition from the surrogate's point of view took many forms including amount of burden endured by the patient, the patient's previous wishes, and the patient's past and present quality of life. Often, the surrogate looked at the amount of burden being experienced by the patient and placed some sort of limit on the type and amount of treatment that the surrogate would allow the health care team to enact. Prior knowledge of the patient's wishes or the surrogate's assumptions about the patient's wishes regarding treatment or a bad outcome from treatment were used to guide the surrogate's decision-making process. Occasionally, the surrogate and the patient had developed a plan for the end of life; however, that was unusual in this study sample. The surrogates were fairly sophisticated in their understanding of the kinds of treatments that were available to keep the patient alive. Surrogates expressed a need to evaluate the patient visually, so as to make their evaluations more complete and to understand whether the treatments being tried would return the patient to the same state of independence as before the last hospitalization.

A few surrogates stated that they considered the burdens associated with various treatments when they undertook to evaluate the patient's condition. Surrogate 6 described

this evaluation process in very concrete terms. The concept of burdensome treatment had been introduced just prior to this part of the interview. For her, the signs and symptoms being experienced by the dying patient were important to making a decision regarding withholding and withdrawing life-sustaining measures:

> I think it took some experimenting with the drugs with Dad [while in ICU], and…once hospice came in and took over the case on medication, it was better. It was much better for us because we didn't see him suffer much. But it was hard before that [while in ICU] to see him suffer and not be able to swallow and choke. That was hard.

Evaluating the burden of her father's suffering assisted this surrogate in knowing that withholding and withdrawing life-sustaining measures was the right decision.

Surrogate 9 spoke about the idea of leaving her husband on a ventilator indefinitely. The thought of long-term life support had been discussed by this surrogate and her husband; both had agreed to limit burdensome treatments:

> He was just going to load me up in the back of a pickup and take me to [name of town] to bury me. And I would do the same for him. That's about all. And we had living wills…Yeah. Yeah. I wouldn't want that [keep her husband on the ventilator]. James wouldn't have wanted it. I wouldn't want it. And I didn't want it for him.

The surrogates' perception that a treatment might be burdensome to a patient can be seen to have played a role in this surrogate's decision to forgo life-sustaining measures.

Surrogates often considered multiple issues in their evaluation of the patient. For instance, Surrogate 2 spoke about the physical burdens on her husband, the limits that she wished to place on his treatments, and how she understood his declining condition:

> ...On that Friday night, they also did ask to begin tube feeding, which I knew was bad…but I knew it was to keep him alive as well…I didn't want to put his body through any more stress. I guess I didn't want him to die on the respirator. That was probably my primary decision maker. Because I had already, I felt that I had already put him through so much with regards to that stupid respirator that I thought the least I could do is take him off of it and let him die without it. And so knowing that he was getting very close to that, I just didn't want him to go through any more.

Surrogate 3 spoke about the idea of leaving his wife on a ventilator after knowing that her illness was terminal:

> Because there's nothing we can do but do that [withdraw the ventilator]. So the worsest thing I think in these cases is the lingering. Because, [it] takes one incident, a person, and you have these people, like you said, the ministers and all this; that just goes on and on and on, and it just makes it too hard for the family. I really think it does. I really think that when the family makes the decision and come out with it, best end of it except for the arrangements for the body.

Surrogate 9 provided another account of this need to avoid lingering and to set limits on treatments for her husband: "I'm glad I didn't have a decision to make that would leave

him hanging. I mean if it had to be, and we all have to go at some point, I'm glad I didn't have to say to take him off and have him live for weeks."

Surrogate 14 showed the conflicting nature of making the decision to withhold and withdraw life-sustaining measures even when she had prior knowledge of the patient's wishes. This surrogate made a decision for her mother with whom she was very close and was the primary caregiver:

> I'm like, no, I want them to save my mother. But then I thought about it and I'm like, no, that's not what she wants because she may be a vegetable. I said, "Then I'm going to feel bad because that's something she already told me."

Surrogates did not always have prior knowledge of the patient's wishes regarding end-of-life care. However, most surrogates were able to make some assumptions about the patient as a consequence of their relationship. Whether explicit or assumed, prior knowledge helped surrogates make decisions to withhold and withdraw life-sustaining measures.

Surrogate 3 related that he had already had a conversation with his wife regarding life-sustaining measures prior to the moment in which he was asked to make a decision on her behalf. His description of the discussion that took place between himself and his children about end-of-life care reveals the power of prior knowledge in guiding decisions when a loved one becomes incapacitated:

> They were all there. And my son, I have four [children]. I have a son and three daughters. And we're always sitting down. I said, "This is a decision that we've made, me and my wife. Yes," I said, "we made it between each other. If you go

first you, you do it for me. If I go first I'll do it for you. And that's the way we made it. That's how we come to that decision."

Surrogate 4's statements also highlight the value of patients giving information to their families prior to their becoming ill:

> And we all as a family agreed not to continue putting her through that. And that decision for us was easy because my mother was very, very clear with what her wishes were in the event that anything were to happen. There was no will [living will], there was no instructions, nothing, other than her conversation with us.

Surrogate 1 made health care decisions based upon her knowledge of what she believed to be right for her husband, rather than explicit instructions regarding end-of-life issues. Rather, her sense of conviction came from her having knowledge of her husband's prior wishes. This surrogate spoke of her husband's love of his profession and his desire to remain mentally intact throughout his illness. When confronted with the idea that her husband would not be able to return to his beloved professional career and that he would most likely suffer mental capacity loss, this surrogate began to question her husband's past comments regarding end-of-life for others and her knowledge that he would want to endure life-sustaining measures:

> Well, from his comments on people that he had heard about what had happened to them, what he had said about that is what I was basing my opinions on. Oh yeah, he would have suffered anything; it would have been worth it. I was telling him, it's going to be worth it to you. I know, I know this is uncomfortable for [you]. It'll be worth it; this will be worth it, just keep on trying. It will be worth it. It

would have been worth it to him. He was brave, he was strong, and he was courageous. It would have been worth it to him to go through anything.

Evaluating the patient's condition against the surrogate's understanding also took the form of ensuring that every chance for recovery had been given to the patient, and many surrogates attempted to keep patients alive even at the potential peril of the patient. Using some treatments or medical interventions caused patients' conditions to worsen or to have an additional condition as a result of that treatment. Surrogate 4 stated, for instance, "They took her [the surrogate's mother] into surgery to… they were going to try to unblock a blocked artery. And it was so blocked that they couldn't do it. They actually broke off a piece of the aorta to do that."

This surrogate also reported that extraordinary means were used to keep her mother alive: "Ten times she went through getting a paddle [defibrillation]. After about the eighth time, she seemed to stabilize, but then it happened again after the 10th time. And her heart was still racing." This story highlights the lengths to which some surrogates in the study were willing to go in order to save their loved ones. Surrogate 7 eloquently described the sentiment that drove these decisions: "And even though my mother was in that kind of shape, I didn't really want to give her up–selfishly I did not." Surrogate 5 stated that he waited to make his final decision, hoping that his wife would show some signs of improvement: "Kept hoping… [that she would] respond…Come back a little so that we could see something."

In each of these cases, the surrogate expressed the need to wait for some sort of physiological response from the patient indicating whether the therapies or treatments

would eventually reverse the condition. Surrogate 1 commented that her husband had tried many therapies, including chemotherapy, antibiotics, and multiple bronchoscopies, to cure his cancer. Surrogate 1 related that, even after these treatments had failed and she had been told that her husband would die imminently, she was still not ready to make a decision because she wanted to be sure that he had received every type of intervention possible:

> [The doctor said that] "He only has one or two days to live." It wasn't true. He went on. My husband went on. Then, they started telling me way back there, "Well, you can't, you'll have to take him off. You need to take him off the ventilator." I said, "No, I'll have nothing to do with it." I wanted to give him every chance. He would not have wanted to [pounding on table] just be taken off the ventilator like that. So, I said,"No, I want him to have every chance."

Finally, Surrogate 17 showed the speed at which some surrogates moved from one expression of the personal domain to another. In this situation, Surrogate 17 told the story of her mother's rapid decline in her final hospital stay. The patient was taken to surgery and found to have much more extensive organ damage than was previously thought by the health care team. This surrogate seems to show the very iterative nature of this process by moving between knowledge of the patient's preferences and evaluation of the future quality of life:

> And so when he told us what had happened, I mean that's why I asked him, "What's the best case scenario if everything goes just perfectly, then what she would be looking at? What kind of recovery period would she be looking at?"

> And then that's when he told us, "You know, not a very good process [in terms of recovery]." And then I did start thinking about how…what she would want; whether she would want to go ahead and, you know, spend those months [in rehabilitation]. And what the quality of her life would be, and if she'd want to do that, and I just didn't think she would want to do that.

Viewing the Past and Future Quality of Life for the Patient

Within this theme, surrogates expressed the desire to weigh the patient's past quality of life with the future quality of life. Signs of physical decline were often a clue to the surrogates that the patient's quality would not be in keeping with the surrogate's or patient's values.

Knowing the patient's past quality of life prior to the final hospitalization had an effect upon the surrogate's ability to evaluate the patient's condition. Some surrogates witnessed signs of a declining physical state before their loved ones entered the hospital for the last time. This knowledge helped surrogates to place the patients' conditions on some kind of meaningful continuum. For example, Surrogate 2 reported, "By the middle of November, he was hospitalized [not the final hospitalization] because he was to the point to where he could hardly walk a little more than a block."

Surrogate 9 referred to the fact that signs of her husband's physical decline were evident months before he died:

> He was beginning to get short of breath when he would walk down here to the boat and have to come back up that hill [at their home]. He was beginning to feel that. And when we were in … [a vacation spot], and he didn't want to walk the

town. He would get in the car and drive from shop to shop and place to place and then get out and come in with us. He didn't want to walk it…But I just attributed that to being older. And he didn't exercise. He didn't do anything that would keep him in good shape really.

Surrogate 7's comments underscore how knowing the patient's past quality of life before the final hospitalization influenced the decision-making process for the future:

I said, "Well, I know her quality of life is terrible, you know. It's not good, you know. If she were to wake up right now, I don't know if she would be like she was when I saw her this morning even, you know." It [life-sustaining measures] can go on and on forever, you know, until something happens, and she doesn't make it. And at that point, that was when I said, "No, I just don't want that."

In addition to considering the patient's past condition prior to the final hospital stay, surrogates also thought about the quality of life that patients would experience after treatment if the patients survived. Many surrogates feared that their loved ones would be required to live in an uncomfortable or unwanted condition. This reservation was expressed in several ways. Surrogate 4, for example, had this to say about her mother's prognosis:

We also gave it [continued care] some thought because my mother…her feet were…her circulation was so bad that she probably, had she survived, would have lost her feet. And my mother would have been very, very angry. And we [family] had talked about that [mother's reaction], that she would rather go than to be

stuck in a wheelchair and losing her feet. She would be upset with us for letting that happen.

Surrogate 3 stated it this way: “Mother immediately said, 'If there's a decision to be made, Daddy would not want to live the way he looked.' The way he… paralysis and him not being able to talk.” Surrogate 5 and her family weighed the patient’s quality of life in consultation with the patient’s physician, and they considered prior knowledge of the patient’s wishes:

> So the neurologist was in this small room, and we [family] were all stuffed in there together. We asked some questions about quality of life for Dad and rehabilitation, what it would be like. He [physician] was very clear what his quality of life would be like, which wasn't good. And he [patient] would never probably be able to take care of himself, ever. And my daddy had always told me that's not what he wanted.

Surrogate 7 also made the decision in consultation with the patient’s physician. However, it is clear that the surrogate had an idea about the patient’s quality of life before the last hospital admission. The surrogate weighed this prior quality level against a potential future quality before making a decision:

> And he [the physician] also said, “We can do whatever you want to do. It's up to you. We [the health care team] can go on. It's endless what we can do. But what is her quality of life?” I said,”Well, I know her quality of life is terrible, you know. It's not good, you know, if she were to wake up right

> now I don't know if she would be like she was when I saw her this morning even, you know."

Surrogate 8 reported on a conversation that he and his father, the patient, had, in which concerns about quality of life in the future influenced the surrogate's decision regarding life-sustaining measures:

> The potential quality of life afterwards... [speaking for his father] "If it looks like I'm [the patient] in pain at the time." Like, if you could just look at my dad and tell, he just didn't want to be there. He was having a real hard time.

This quality of life was clearly not in keeping with what the surrogate valued for his father.

Finally, Surrogate 13 was able to relate common concerns of many of those who had to make a decision for a loved one. When talking about his wife, he was able to show how the evaluation of quality of life was pivotal in making a decision:

> It was the neurologist. When I finally talked to him on the phone, he said, "I can tell you conclusively that had she overcome the immediate crisis, her quality of life would have been zero." So that was not good to hear, but it confirmed our position, at least in my mind, that we were doing the right thing by not going to artificial [life support]…

This critical point in the surrogate's decision-making process is linked to a similar step in the Intensive Care Environment domain (see next section). At this juncture, the surrogate ends the iterative, back and forth movement between the personal domain and

the intensive care environment domain. The surrogate may have initiated this step without prompting by the health care team; or the health care team may have initiated a review of the patient's potential medical outcome with the surrogate. A more thorough explanation of the relation between these two steps is provided after the discussion of the corresponding portion in the intensive care environment domain.

This personal domain represents a large portion of the work done by surrogates in making a decision to withhold and withdraw life-sustaining measures for a loved one in an intensive care environment. This domain is illustrative of the processes that surrogates used to engage significant members of the surrogate's and patient's family; this domain was where surrogates were able to engage in inward reflection about the patient and the need to withhold and withdraw life-sustaining measures. Surrogates' families provided support to surrogates, even if the families were not present at the actual time of decision making. Surrogates shared health care information with families either during or after the patient was in intensive care. Having the assistance of family members was helpful to surrogates in seeing the futile nature of continued aggressive care. This recognition of futility ultimately led the surrogate to make the decision to withhold and withdraw life-sustaining measures.

INTENSIVE CARE ENVIRONMENT DOMAIN

The term *intensive care environment domain* is used here to represent more than just the physical space where care was delivered. This term is used to represent the surrogates' activities and actions as they interacted with nurses, physicians, social workers, therapists, and other members of the health care team, as well as family. This

term not only is used to describe the personnel but also the environment in which the surrogate found information and learned about the patient's condition. The intensive care environment domain includes the waiting areas and the private consultation rooms used by many physicians to discuss withholding and withdrawing of life-sustaining measures..

Chasing Doctors

This theme represents the surrogate's work necessary to obtain information about the patient in the intensive care unit. Most of the surrogates reported that they had to make concerted efforts to obtain information about their loved one's condition, diagnosis, and prognosis. Surrogates expressed frustration with their health care teams, as they believed that information vital to the decision-making process was not readily shared with them, was often presented in jargon, and was conflicting or contradictory. This seemed to anger many surrogates and ultimately hamper their decision making.

Surrogate 2 gave a tongue in cheek account of seeking information from the health care team. She called this process "chasing doctors." While seemingly humorous in her words, the intent behind this surrogate's need was clearly evident:

> When you're under that kind of emotional stress and you're chasing doctors [laugh]. You know the last thing you're really, you just not up to chasing after people. You know? It's just too hard. And so it would help if those people could see you a little bit more.

This level of effort was not unique. Surrogate 5, for example, reported, "[I would] try to catch the doctor in the hall to get a word out of him. I'd just have to come chase him down."

Surrogate 3 portrayed his health care team as hiding information and as operating with spurious intent. He described how he was informed about the terminal condition of his wife:

> Thirteen o'clock came, and nobody said anything to us at all. So I got up, and I'm walking down the hall through the hospital, and I met the doctor…But we met in the hall and I said…"Doctor, how's my wife?" I said,"Nobody told us anything." I said,"They just had me waiting." He said, "Oh, I'll go up and see about her." My wife was already dead. She was already brain dead. They wouldn't tell us. I don't know how long she had been in that room brain dead. They didn't tell us a thing. If I hadn't had met him in the hall, I don't know when they would have told us. And that's the hurting part, you know?

Surrogates expressed the desire to make connections with heath care team members and particularly with physicians. Surrogate 6 reported:

> I didn't talk to the neurologist until after the surgery…when I was trying to get a hold of a cardiologist. I was just grasping at that point, trying to find Daddy's doctors to see what was going on. Yes, I needed information, and this gentleman [the physician in charge] did not provide it; was not helpful.

Many of the surrogates spoke about the need to spend additional time in the hospital to obtain information. One surrogate would violate visiting hours to see physicians. Surrogate 1's husband was in the hospital longer than any of the other patients described in the study. She offered the following account of her experience:

> I had to go back there when I wasn't supposed. I would just march back there at 8:00 in the morning, when I figured out when the doctors would be around…I would just go back there and go up to them and see what I could find out. They weren't going to instigate it unless there was some immediate crisis. They weren't going to come looking for me. I want to know every day. I want to know what they see. I want to know what they're finding out. I want to know all about it every day. So, I would just go back there every day, and just get in. I would just go back there and ask them.

Surrogate 8 also spoke about waiting in the intensive care environment to obtain information regarding his father. "I mean, I spent a lot of time sitting there, but I was getting calls from my cell phone constantly from, you know, (family)." Surrogate 4's comments highlight the degree of emotion that can be elicited during the process of attempting to get information from physicians and health care providers regarding a dying patient:

> And of course, it's not always easy to see all those doctors, you know. They're in and out at weird times and you've got to practically plant yourself there to make sure you see somebody…And we also demanded.. I passed the point [of being patient] where I simply had a demand an appearance [from the physicians]. You know, when I could be there. You know, I mean, not maybe at 6 a.m. in the morning, but 8 a.m. in the morning or whatever because I wasn't getting any answers.

While the surrogates wanted as much information as possible about the condition of patients, they also reported feeling frustrated when their physicians offered conflicting opinions. These discrepancies frequently caused surrogates to mistrust their physician teams. Surrogate 2's account of her loved one's transfer of care from one city to the Austin area illustrates this point: "The other thing that I found had happened… [we] had a lot of doctors and a lot of different opinions. And it was extremely frustrating. Oh yeah. At least in [a previous hospital in another city] they all pretty much agreed." Surrogate 1 stated that she was confused by the contradictory statements of the physicians, and this confusion must have delayed her decision to withhold and withdraw life-sustaining measures from her husband:

> One thing that was really upsetting was that people would tell you different things. Dr. [X] said--I asked him what he thought it was--and he said,"Well, maybe he had a stroke, maybe there was bleeding on the brain." I asked several people what his mental capacities might be like. Some people said,"Well, there's no reason to think that there might be damage." Another person would say,"He will never be the same again," on and on like that.

Surrogate 8 had a similar experience. He described the changing perspectives conveyed to him by physicians and other members of the health care team about his loved one's prognosis:

> And every day it changed, you know. They think he's going to make it. They're pretty sure that he's going to recover. It's not looking so good; I'm sorry. You

know…he responded well to today's dialysis. They're saying he'll probably live another year or so. Another six months maybe. Maybe a month. You know."

Even if the information was contradictory from one physician to anther or from one day to another, obtaining information from the health care team was vitally important. As previously seen, this information was then shared with the surrogate's family. In most instances, the surrogate needed to hear that the family understood and agreed with the surrogate.

Many physicians used language that surrogates did not understand, and in so doing, they may have unduly influenced surrogates to delay treatment decisions. Surrogate 8's account contains the best description of this phenomenon:

> Umm… no, he's [physician] saying something I don't really understand…And he's using these big doctor words. I have a fairly large vocabulary, but I don't know all the nicky-nickel and scientific words for organs and stuff. And then finally I'm picking up every other word…and I finally realized that what he's talking about is…There's nothing we can do for him. He's going to die.

Surrogate 8 ultimately used his own understanding to make a decision in regard to his father's care. One can see how this decision might have been affected by the surrogate's lack of comprehension of the physician's comments. When surrogates misunderstand or do not comprehend what the physician is saying, surrogates may make decisions that are not in keeping with the patient's and surrogate's true values. Decisions made with information that is not understood may result in either premature or delayed decisions:

> And I, you know, over these 20 minutes [reflecting on what the physician had said] I've been sitting there by his bed watching him writhe around, thinking about it being like, "Dad, I know you told me last weekend you wanted to stay alive for a month, but the doctor's telling me there's no way. And, you know, you're obviously exceedingly uncomfortable now. And I don't know what to do. I don't know what to do."

Within minutes of witnessing his father's pain, the surrogate made a decision to withdraw the ventilator and vasopressive medications from his father.

Surrogate 7 also spoke about the language used by health care providers. However, she elected to ask for clarification rather than accept the explanations being offered to her:

> Whenever I was there…the liver doctor was pretty forthcoming, as far as what he thought, like diagnosis-wise. I remember asking him a lot. You know,"Could you explain this to me? What does that mean? What is… what's the prognosis?" I remember asking a lot while I was there at the hospital.

Finally, Surrogate 13 describes the frustration with the language that was being used to describe his wife's condition. His wife was close to dying when the oncologist came into the room:

> I don't know what the terms are, but that's when all hell broke loose. And [I] ran into intensive care. And they were telling me this and that about the whole situation and I just asked the pulmonary doctor, I said, "A lot of these terms go

over my head. Is the tube in the right place?" He said, "No, it is not." It's that plain…That I could understand.

Expressions of the Surrogate's Relationship with the Health Care Team

Within this theme, surrogates expressed a variety of relationships with the health care team. However, many surrogates expressed that they were angered by members of the health care team particularly by physicians. While not completely without tension in the relationship with surrogates, nurses were most often seen as supportive and caring of both patients and surrogates. Surrogates expressed a desire to participate in all treatment decisions. These relationships eventually resulted in learning to trust the health care team and ultimately assisted surrogates in moving forward in the decision-making process.

The surrogate's relationship with the health care team was often marked by feelings of discord within the intensive care environment. Numerous surrogates reported that they had difficulty trusting physicians because they delivered information about the surrogates' loved ones in a manner and tone that the surrogates found objectionable. Surrogate 4's response to an interview query about the worst part of her hospital stay was typical:

> The relationship with the surgeon…And he also made comments like, "I can't believe she's [the surrogate's mother] still living. I mean, I can't believe she's still living."...He really upset me, and not just my… the rest of my family. He was very… too matter of fact, too blunt. "Your mother's going to die."

Not all surrogates expressed negative feelings toward physicians. Surrogate 2 related that she felt a sense of respect for a particular physician after there had been confusion within the health care team regarding the plan of care for her husband:

> Sunday morning early I got a phone call. The pulmonologist told me that he didn't think he [the patient] was going to make it through the day. The primary pulmonologist, who knew everything that I had gone through the earlier week with the on-and-off stuff and all the craziness. And he was extremely apologetic and extremely compassionate. [He was] the most compassionate and sensitive of the situation we were going through.

Not all surrogates spoke about physicians. Surrogate 9 reported that she was comforted by a social worker:

> I guess I think the social worker came in. Very nice. Came in, and she arranged it so I could go right in and see him...The social worker really handled everything very well. She was young. She was very comforting. I talked to that social worker. She came in several times and very nicely offered us water and so forth and asked if we were comfortable while sitting down in that little room.

Other surrogates reported feeling outright anger with their physicians. Surrogate 6, for example, described her difficulties obtaining information about her father:

> This doctor called and basically…said he had been working hard all day long, and that he really didn't see any need to talk to me about this. He had read the report or something. He didn't need to talk to me. He was so rude and insensitive…I was just blown away at this man being so rude and insensitive to me…He was being

bothered that I bothered him, that he had to call me. I was so upset...That was really hard on me, too.

Surrogate 7 related a similar experience. So angry was this surrogate that she wanted to physically hurt the physician on call, who was caring for her mother:

> And the doctor came in…And he said something to the effect that this should have ended in [our hometown]. And I don't know why, and these are not his words, but this is what he meant: "They're passing the buck to me." And I said to him, "I beg your pardon?" I mean, I didn't care who he was. I thought, "You are so rude. How dare you?" My tone of voice, or maybe my tone of voice and the look I gave him, I don't know, but he seemed to catch himself and not go there again. But I could have slapped him. And he probably needed it, wasn't very nice.

Even when there was a relationship with the physician preceding the last hospital stay for the patient, the surrogate had difficulties maintaining the amicability of that relationship. Surrogate 6's story about her father's physician of many years is illustrative of this theme:

> But I thought, to me, his cardiologist should be in on [this], that his patient was there in the hospital. I called the office to let Dr. [X] know my dad was being taken by STARFlight. They never called, they never checked on us. Not one word. Nothing. Nada. That was disappointing. He's your patient; he was at the hospital…Come, call; see what's going on. Nothing. So that was disappointing.

Not all surrogates were angry only with physicians. A few surrogates stated that they had difficulties with nursing staff. From Surrogate 1:

So, Friday after they left, he began to have trouble breathing. He said, "I want to see a doctor. I want to see a doctor!" The nurse, I will never forgive this nurse. I will never forgive myself, because the nurse was very condescending. She didn't come in there to see what was really wrong with him. She called down there and she said, "The patient is demanding to see a doctor. His wife is demanding to see a doctor." Not–She didn't come in there to see what was wrong with him. She didn't come in there to assess if he really needed [a doctor]. She didn't say to that doctor, "I think you should come because there's a problem." She didn't even come to see. I'm sorry, but you never get over this.

While many surrogates expressed anger with health care team members, other surrogates used the health care team to ameliorate their anger. Surrogate 2 characterized the team as crucial to helping her glean information and overcome her confusion about contradictory physician opinions:

> …It wasn't the primary pulmonologist that was involved in making the primary decision. It was one of his associates, who wasn't really communicating with me at all. I was hearing more things through the chart and through the nurses and through the oncologist, and at this point, I was pretty frustrated.

With few exceptions, nurses were seen as helpful and comforting to surrogates and their families. Many examples were cited of the compassionate care that patients and surrogates received from hospital nursing staff members. The kind gestures that were recounted outweighed the anger and frustration that surrogates recalled experiencing with

the health care team. However, Surrogate 2 voiced reservations about the nursing staff that cared for her husband:

> The nurses were, some were great and some were awful, quite frankly. I know that a hospital is a place where, you know, it's a business. They have to have some rules, and they have certain ways of doing things. But when you're talking about someone going into bed dying, it also required compassion. And there were some nurses that were, they were in the wrong place with regards to that. They might have been good at their job, but they, you know, they were…I'm not sure the appropriate word to use. Nurse bashing is a word that comes to mind [laughs]. You know, I mean, they were just so…rigid, you know, deep into the responsibilities of their job that, you know. They probably were giving great nursing care. I don't question that.

Surrogate 10 spoke about the nursing staff's efforts to make sure that her sister was comfortable in the final stages of dying:

> I think they was coming in every hour. Because, like I said, those people [nurses] had done everything they could to make sure she was comfortable. One thing I asked them to do, could they please come in every 30 minutes and just turn her so she could, you know. And they'd done that. They'd done all they could to make her comfortable.

Surrogate 7 had a good experience with one nurse in particular. This surrogate's story illustrates the role of the nurse in caring for the patient, as well as the surrogate, in

intensive care environments. When she was asked during the interview if anything went particularly well while she was in the hospital with her mother, she had this to say:

> Yes. There was a nurse in ICU. And she really, really, really stands out in my mind. She was very comforting to me. She was very sweet with my mother. She was just very nice, very soft-spoken, very sweet, very sensitive. And I know that they see that all the time. And they see families go through this all the time. But we're on the other end. We're on the other end, and we're hardly ever there, thank goodness. But she was just always asking me if I wanted to call anybody, did I want her to call anybody, you know. Could she do anything for me. And I even got off without my coat. And I went outside, and she loaned me her coat. I don't know, she was just nice, very nice.

Surrogates relied on the kindness of the nurses even beyond the time when care was actually being delivered to patients. Surrogate 4, for example, reported:

> I loved the staff. Every single one of those nurses brought their own personal… they actually personalized it with us and for us. They gave their own personal situations in how they handle their own grief. And one nurse had a sister who was dying of cancer. Another one had lost her mother. I remember asking a nurse for a lock of my mother's hair, when they had given her a bath, and I said, "I hope you don't think that's, you know, inappropriate." But… and she said, you know, "Absolutely not," and then, her religion and the country she came from, that's normal, that's the standard practice. And that made me feel better, by the nurses sharing their personal experiences. And I wrote a letter to the hospital, and I

mentioned every single nurse I named, and what special thing they brought to our room.

Clearly, care for the surrogate is as important as care for the patient in intensive care environments. Whether small or large, hospital nurses' gestures made a lasting impact on all of the surrogates.

Relationships with the health care team were sometimes fostered by participating in each and every decision regarding the care and treatment of the patient. This ability to participate in patient care seemed to help the surrogates feel that all possible opportunities for treatment had been offered to the patient and thus led to increased trust in the physicians and the heath care teams. When surrogates were deprived of the chance to make decisions on behalf of their loved ones, however, their confidence in hospital personnel, and in their own power as surrogates, suffered: Surrogate 2 offered this insight:

> By Tuesday though, they were trying to wean him off of the respirator, and they knew he didn't want to be on it. And because he was alert enough to express that, they really were following his directions. They took him off of it. And they took him off pretty much without telling me. They had said that they were thinking about it. But I came back from someplace and he was off of it. I was disappointed that I wasn't… that I didn't really have more of a say in it.

Surrogate 8's story highlights the importance to surrogates of being involved in patient care even when surrogates are unable to be physically present:

> But the prognosis, I wanted to know any time they had information, and ask them to call me and tell me. So, I always got four or five phone calls a day. But I don't know if the doctors, when they came by, they [the patient's physicians] were like, "Here's what we're saying today."

Both the relationship with and the information received from the health care team evidently represent vital components of the level of trust that ultimately develops between hospital personnel and surrogates in intensive care environments. According to the surrogates interviewed, the amount of information that was offered and the quality of the relationships cultivated between health care personnel and surrogates ultimately affected how much trust was established with health care providers. Surrogate 2 and her husband, for example, reportedly had a prior positive relationship with their physician in another city, and they relied on this relationship, rather than the opinions of their current physicians, to assist them in making a decision regarding ventilation. It is clear that quality of communication influenced the development of trust between physician and surrogate in this case, and that trust, in turn, had a critical effect on the surrogate's decision-making process. Surrogate 2 stated:

> I didn't feel like I could trust any one of them [the physicians], because they weren't communicating with one another… He [the surrogate's husband] didn't know any of these doctors. The only person he trusts was his doctor in [our home town]. And he continued to tell me, "Whatever my doctor in [our home town] says to do, that's what I want to do." And so I did call him, and I said, "This is what they're telling me. What do you think?"

It can be seen that, when there is a trusting relationship with a physician, the surrogate has an easier time making a decision. Surrogate 4 confirmed the notion that making a decision to withhold and withdraw life-sustaining measures is made easier when trust in a physician exists:

> And we decided that, since her heart was gone, and at this point, the cardiologist who we had really [come to] trust was very honest with us in a very nice way that helped us make our decision. And so we did.

Surrogate 12's account of her husband's receipt of blood transfusions demonstrates that blind trust in physicians can also exist, but that even this sort of trust is based at least in part upon prior knowledge of a patient's condition.

> Well, I believed what they said, because he's already had a few transfusions. So I just trusted their judgment when they said he might not make it. And he seemed, he seemed so sick, and I trusted that they did know what they were saying…They had never given me [the option to use a ventilator or CPR]. They just said that they were going to put the [dialysis] machine on him to try to bring him back. They believed there was no reason to [do CPR]. He was already too sick. Um. I just believed and trusted everything that they were saying.

The Health Care Team Confirms the Probable Medical Outcome of Continued Treatment

This theme is represented by the surrogate being told of the patient's expected outcome once the health care team comes to the understanding of the terminal nature of the patient's condition. This step was difficult for surrogates to comprehend, and many

surrogates were given this information more than once. However, until the surrogate reached a point in the process in which this information was received and acted upon, the surrogate did not progress in the decision-making process. Surrogates often needed to hear repeatedly that the patient would not recover and would die with or without life-sustaining measures. Hearing the confirmed terminal nature of the patient's diagnosis was a critical part of the surrogate's decision-making process.

Without using a word as overt as "terminal," the physician often was able to convey the idea that a terminal diagnosis was present. Within the study interview, Surrogate 9 related the story of hearing from the physician that her husband was terminal. While sitting at a game table in her living room and with her aged poodle dog draped across her lap, she spoke:

> But the doctor came up and he kneeled down in front of me [surrogate gestures as if the physician is present] because I was sitting in a chair by that time, and he told me what had happened. And I said [looking at the imaginary physician], "Well, is there anything that can be done?", and he said, "No"… I guess he just told me what happened using the terms like cerebral hemorrhage in the back of his neck…

Surrogate 16 told the story of making a decision to withhold and withdraw life-sustaining measures for his wife who was ill with cancer. This surrogate showed the power of reliving the time when the surrogate heard the poor outcome of continued treatment:

> Then Doctor [X] called me aside and says, "There's not anything more we can do. It's just a matter of time. Her kidneys are starting to fail." He says, "When the organs go," he says, "one organ goes, another organ goes. The kidneys have gone now. They're not functioning." [Crying] And he says, "That's what we're looking at." [Surrogate then asked to have the recorder stopped for a few minutes] Kind of like reliving… [Sobbing now].

Surrogate 10 told the story of making a decision for her sister. The physician and surrogate were engaged in a conversation about treatment options:

> Oh, very important [to hear the diagnosis confirmed], because if they thought, you know, that there was something they could do to make Betty, you know, better. Yes, I would of thought, but I mean, he just let me know she's going to die even if we do the surgery or not. So, and like I say, I just didn't want Betty to suffer…It made the choices easier, but at the time, no. It was something I didn't want to hear.

Surrogate 5 related the idea that his wife was not going to return to a state of health after hearing from the physician about his wife's inability to maintain an oxygen level:

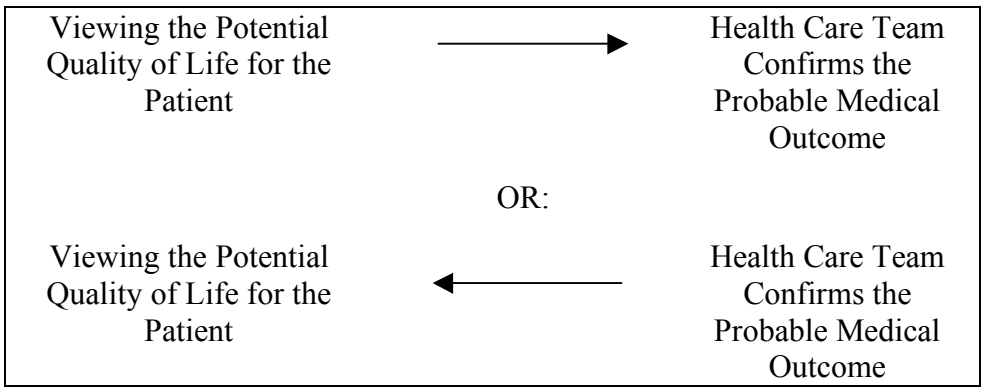
> The biggest decision to me were the increase in requirement for oxygen. It required more and more oxygen, which means we're less and less capable of breathing or whatever. The tests [x-rays and blood work] were continuously to be good. At least according to what they told me. She just wasn't… she just wasn't coming back. I'd say afterward that the decision had to be made…So me and the

doctor, we talked about it a little bit. Then we turned it [oxygen and ventilator] off. They told me afterward that turning it off was the right decision. That's some dirty boots. There was no right time.

As previously introduced at the end of the Personal Domain section entitled Viewing the Past and Future Quality of Life for the Patient the surrogate reaches a critical point in the process which moves him or her into the final parts of the process, the Decision Domain. Viewing the Potential Quality of Life for the Patient is related to Health Care Team Confirms the Probable Medical Outcome of Continued Treatment in the Intensive Care Environment Domain. The health care team may initiate a discussion about the patient's potential medical outcomes based upon current health care practice or the patient's condition. However, the surrogate may initiate a conversation with the health care team about the patient's quality of life from the surrogate's point of view. Figure 4.1 shows the way in which these two interrelated steps may be initiated:

Figure 4.1

Interrelated Steps of the Two Domains



Whether initiated by the surrogate to the health care team or by the health care team to the surrogate, the exchange between the surrogate and the health care team provides the last bit of information needed by the surrogate in the evaluative process. Both of these steps allow the surrogate to progress to the next step and domain in the decision-making process.

In summary, the intensive care environment domain represents the surrogates' activities and actions as they interacted with members of the health care team and with family. In this decision domain, surrogates were able to obtain information about the loved one that was crucial to decision making regarding the withholding and withdrawing of life-sustaining measures. However, many surrogates expressed the feeling that they were “chasing doctors” to obtain that information necessary for decision making. When jargon or technical language was used by the health care team members or when physicians gave conflicting opinions regarding the patient, surrogates often expressed animosity toward health care team members. However, nurses were most often seen as supportive to surrogates, and nurses assisted surrogates to establish an understanding about patients' conditions. Surrogates expressed a desire to participate in all decision regarding treatment; they eventually learned to trust information from the health care team that stated the patient was terminal. This realization of futility led the surrogates to move into the next step in the decision-making process and the next domain.

DECISION DOMAIN

This last section, *the decision domain*, represents the activities used by the surrogate to make the decision to withhold and withdraw life-sustaining measures from an incompetent patient This domain included three themes: (a) the surrogate's arriving at a new belief that continued care is futile, (b) retreating into one's self to make the decision to withhold and withdraw life-sustaining measures, and (c) communicating the decision to the health care team to enact withholding and withdrawing of life-sustaining measures. This portion of the surrogate's experience of the decision-making process was linear in nature, and one event triggered the next to happen.

Arriving at a New Belief

In this theme, surrogates often evaluated the patient's condition through watching for physical signs of decline. Additionally, the patients described in these interviews often displayed signs or symptoms that allowed surrogates to comprehend that death was imminent. Through this process of observation, surrogates came to a new understanding or belief about the patients' ability to survive or to live meaningful life. However, this theme was also represented by surrogate's expressions of uncertainty, guilt, and disbelief.

Surrogate 1 seemed to describe having the earliest premonition of her husband's death based upon physical signs:

> He was also having problems with his kidneys. At that point, his kidneys had really stopped working on the Tuesday. I thought, "Oh, this is it; he's going to die. He's going to die today. His kidneys aren't working; he's going to die."

Surrogate 8 described recognizing more obvious signs of impending death:

> And my dad, his tongue was hanging out, and his lips were cracked. I mean real cracked, and it was gross. And his teeth were sticking out, and he would [moans] and he'd moan. And try to…had to sort of restrain him several times because he's banging his arms [on the side rails].

Surrogate 3's account illustrates how simple the process of arriving at a new belief about continued care can be:

> He [the physician] said, "Your wife didn't pull through. She is brain dead," he says, "and what we mean is, you know, she's brain dead. All her body activities are gone. I want you to know that…I just want you to know this, that there's no other activity. She could be dead in two days, three days, and maybe even a week." He says, "We really don't know. But there's nothing else we can do." And I can understand that.

Surrogate 4 saw the futility of continued treatment in terms of the patient's ability to recover. In this case, the surrogate did not feel that her mother would recuperate from a devastating surgery: "They took her back into surgery. They looked to see, they closed her sternum, and they came back saying the whole right side of her heart was dead, and that she wouldn't be able to recover from that."

Surrogate 5 seemed to know when to stop life-sustaining treatments for his wife, based upon the amounts of treatment being delivered to her. The failure of the treatments to achieve any appreciable effect helped him to make a decision:

> I asked them to give her more oxygen. And the doc said, "That's as much medication as we can give her." I asked them how the…what's the reason she's

like this. But the doctor kept saying that he couldn't give her any more medicine. Mostly it would be illegal. And then they asked me if I wanted them to give steroids to her. They'll ask us if we've got to raise the oxygen again. I said, “That's enough.”

Arriving at a new belief about the patient was also accompanied by uncertainty and guilt. The surrogates seemed to second-guess their decisions. Surrogate 1, for example, expressed insecurity about her resolution to stop life-sustaining measures for her husband. Her comment highlights the ambivalence associated with this kind of decision making in that Surrogate 1 both doubts and trust the rightness of her decision:

> Because like I said, there is no such thing as zero [chance of survival]. He would have told me that. He [the patient] was a scientist. Like my daughters said, “Yeah, but it was so close to zero it didn't matter.” They firmly believe that we did the right thing. That he [the patient] could never have gotten well. Some days I think about that, and I think he couldn't have gotten well. You know, there's no way he could have gotten well.

Even though his father had given his son, the surrogate, specific directions related to life-sustaining measures, Surrogate 8 made a choice to forgo treatment for his father. Surrogate 8 expressed guilty feelings after making the decision:

> I’ve been sitting there by his bed watching him writhe around, thinking about it being like, “Dad, I know you told me last weekend you wanted to stay alive for a month, but the doctor’s telling me there’s no way.” And I told the doctor, “Okay,

> I mean, if you're sure that all it's going to be is pain from here on out, then do it [stop life support]."

Surrogates discussed experiencing a backlash of contradictory feelings after arriving at a new belief about their loved ones. Surrogates often remarked that they entered into a state of disbelief once they concluded that continued care was futile. Surrogate 7 articulated this feeling particularly clearly:

> I thought, "I can't believe this. I can't believe this is going to happen right here right now. Right in front of my eyes. I can't believe it." It was still... Yeah, it was. It was horrible. I just sat there, and I cried and cried and cried and cried and cried and held her hand and kissed her.

Surrogate 9 also reflected on her feelings of disbelief after making the decision to forgo treatment for her husband:

> So I think I was already pretty well prepared for what I was going to find, even though it's a total shock. When you see somebody, you're discussing your Christmas presents, and he leaves, and all of a sudden, you get that call. It's just…it's an unbelieving world. It really is.

Finally, Surrogate 9 told the story of feeling that she had no other decision to make other than the one that she made for her husband:

> If he hadn't had been put on life support, he would have died before I got there. And so there wasn't anything that I could do to save him. There was nothing that could be done or that they could do. There was no operation.

Getting Alone to Make the Decision

In this theme, surrogates spoke of the need to retreat within their own mind to weigh all of the information that they had received up to the point of deciding to withhold and withdraw life sustaining measures. This retreat did not necessitate being physically alone. Surrogate 8, for example, talked about needing to make the decision for his father on his own. Even though he wanted his family to join him at the time of the decision making, he did not feel the need to have others, namely his sister, agree with him:

> So I called my sister and it was like, "Get over here now." I called my grandma and my aunt and was like, "Get over here now." And my sister got there; she was in the parking lot when I called her. And so she got there. And I told the doctor, "Okay [stop the ventilator and dialysis]." So it was really important for me to have people there as far as like sharing the grief or whatever. Not the decision. The decision I felt like was mine [pause]…and my sister's and that my sister, I guess, [I was] protecting her and having to make it [the decision]…

In making her solitary decision, Surrogate 2 seemed to weigh the burden of treatment and then arrived at a sense of personal certainty about when to stop treatment for her husband. In the following passage, Surrogate 2 describes how she retreated into her own mind and then came to a conclusion about how she should proceed:

> Well firstly, when I said it was my decision, I say that because we [surrogate and family] didn't consult anybody. I didn't say, "Do you think we should stop now?"…I knew when that point came that I would know when it was [points to temple].

Surrogate 15 showed the need to be physically alone to make the decision regarding her husband. The physician in charge of the patient's care came to the surrogate the afternoon before the patient died. The patient was to receive a heart transplant, which did not happen:

> The afternoon before, Dr. [X] and [the transplant coordinator] and I had sat in an empty ICU room and said, "You know, this is what we're doing if nothing works. What is going to be your decision and everything?" And I had told them, I mean I had already, I said, "Give me a few minutes…Give me a few minutes alone." They left me in that room by myself. There was a time when I could just sit there. [Gesturing toward the ceiling] It was almost like I was talking to God, you know?...So it was my time to get that straight with God [clasps her hands together]. And because I really felt like, you know, we're going to get a new heart, we're going to go home…And it was almost like God said, "No. He's not getting a new heart. I'm taking him home, you're not." And it was like that at that point, that resolved it for me.

Finally, Surrogate 1 gives the most poignant description of needing to be alone mentally and physically to make a decision for her husband:

> As far as like, oh, when I finally decided the process, I felt, I mean I just went outside and tried to think by myself. I thought if I think about this all by myself I'll be able to decide…

Communicating the Decision to Withhold and Withdraw Life-sustaining Measures

Communicating the decision to withhold and withdraw life-sustaining measures is the last of the themes presented. Once each of the surrogates had made the decision to withhold and withdraw life-sustaining measures, the decisions were communicated to the health care team. This ended the actual decision-making process; however, the surrogates interviewed demonstrated a need to say goodbye to the patient immediately after having made the decision to withhold and withdraw life- sustaining measures. This part of the process tended to take place soon after the surrogate had comprehended the potential quality of life for the patient, and the health care team had confirmed its opinion about the patient's prognosis. This was often followed by feelings of being disconnected from the patient, family and health care team members.

Surrogates did not always communicate the decision to withhold and withdraw life-sustaining measures in isolation. The following comment from Surrogate 9 highlights how families participated in the decision making and in communicating with the physician about end-of-life decisions:

> I guess when I asked him [patient's physician] if there was any hope and he said no, there was no hope, then I said ,well, we can't leave him like this, I guess. And I know that we all three decided, and my daughter-in-law, too, of course, we all three decided that we wouldn't just leave him hanging like that.

Surrogate 6 related the story of hearing her father's futile diagnosis confirmed by the neurologist and then having her family help her to communicate her decision to withhold and withdraw life-sustaining measures:

> And after the neurologist answered everybody's questions, and I had it written down, and if anyone had any other questions, they went ahead. So I just looked around at my brother and said, and looked back at the doctor, and said, "You know what we need to do." And everybody started crying and hugging each other. And the neurologist, he was… I think so supportive and very appreciative of our questions…

Surrogates rarely communicated directly with the patient that the decision had been made to forego life-sustaining measures. When patients took longer than a few hours to expire, however, surrogates and their families sat in vigils with them. For example, Surrogate 6 tells about her mother saying goodbye to her father:

> It [saying goodbye] was probably the hardest thing I ever had to do in my whole life. To see the tears [on the patient's face as a result of coughing]. And my mother brought these two little heart pillows from home - a blue and a pink. A blue heart satin with ruffles around it. Lace. And she would put it next to his head and she would comb his hair. She would spruce him up…

Surrogate 12 made the decision to forgo cardiopulmonary resuscitation for her husband. She allowed the health care team to transfuse her husband but did not tell him that he was dying: She commented, "That makes me feel better that I didn't tell him that thing [that she had made the decision] at the end because, you know, because I didn't say nothing because I didn't want nothing to go wrong. I didn't want nothing to go wrong."

Surrogate 1 reported that once she had made the decision to withhold and withdraw life-sustaining measures, she felt disconnected from those around her. In fact,

she behaved as if she were distanced from the study interview itself when the subject arose about arriving at a new belief about continued care. She remarked:

> I think I was stunned. I think I wasn't really totally with it. I'd been there a long time. I told my children, "I feel like I'm in a play." I just wasn't, I just--and it didn't seem real. I don't know how to explain it to you. I don't know how to say it to you. I mean, I said, "I think I feel like I'm in a play," which should have tipped somebody off that maybe I shouldn't have made this decision right now. What was your question to me?

Surrogate 9 also discussed feeling disconnected. In response to a question related to whether she felt unreal as she was making the decision, she said, "I think so. Kind of out of myself. Yeah, I think… I think… I think I was for six months after that. Yeah, I think so.

Along with coming to the belief that the continued care of the patient was futile, surrogates also came to the conclusion that they had made the right, or best, decision about forgoing treatment. Common to all surrogates was the simultaneous feeling of certainty about the decision and guilt about indecisiveness. Surrogate 3 articulated this phenomenon in the clearest manner when he described his decision to withdraw ventilator support for his wife after hearing that she was brain dead:

> And I think if I had to do it all over, I would have to do the same thing. I'm glad we'd done that. I'm really glad we'd done it because like I say, it could cause an animosity in the family. It could cause a terrible animosity, and we knew this. That's why you come to these kind of decisions. You make these decisions to

keep down stuff like that. Because it can bring a hatred in the family that would never get out of it.

Surrogate 5 talked about his sense of having made the right decision based upon the visible signs that his wife was not going to recover from a massive coronary or cerebral event: "It required more and more oxygen, which means we're less and less capable of breathing or whatever…She just wasn't… she just wasn't coming back. I'd say afterward that the decision had to be made."

Unlike the iterative nature of the personal and intensive care environment domains, the decision domain was linear in nature. The surrogate was able to arrive at a new belief that continued care for the patient was futile even though they were plagued by feelings of guilt and uncertainty. Surrogates retreated into their own minds to reflect upon all of the information they had received, and they expressed a sense of disbelief about the process. Once the surrogate made the decision to withhold and withdraw life support, they communicated the decision to the health care team and said goodbye to the patient.

THE GROUNDED THEORY:

How Surrogates Make the Decision to Withhold and Withdraw Life-Sustaining Measures in a Catholic Intensive Care Environment

Surrogates in this study demonstrated a process that has been synthesized into a grounded theory explanation as to how surrogates make the decision to withhold and withdraw life-sustaining measures in a Catholic intensive care environment (see Figure 4.2). Surrogates move back and forth between the familiar personal domain and the

unfamiliar and often frightening domain of the intensive care environment. At the end points of these domains, a nexus occurs and surrogates are moved into the decision domain. The movement of the surrogate into the decision domain ultimately assists him or her to make the decision to withhold and withdraw life-sustaining measures from an incompetent patient in the intensive care environment.

Interacting in the Personal Domain

Within the personal domain, surrogates interact with family and self to come to understand the patient's condition or disease. Surrogates' families are rallied to assist the surrogate with opinions about the patient and possibly to aid the surrogate in recollection of the patient's wishes regarding the end of life. Surrogates seek others' opinions about the patient and the desire to continue life-sustaining measures. Surrogates obtain family agreement about the course of action for the incompetent patient and often experience a bonding with family and others in the intensive care waiting areas and environments. Surrogates evaluate the patient's condition against their own understanding of the situation. In this evaluation, surrogates weigh the burdensome nature of treatment and have a need to know that the patient has received every possible chance for a cure, or at the very least, amelioration of the condition. Surrogates compare the evaluation of the patient's condition with any prior knowledge of the patient's wishes and whether or not there was a plan for the patient's end-of-life care. Additionally, surrogates evaluate the patient's condition against preconceived ideas about limiting life-sustaining measures. The conclusion to this domain occurs when surrogates are able to visualize the patient's potential quality of life. This one step in the process is connected to the intensive care

environment domain in that health care team members and the surrogate discuss the potential medical outcome for the patient. The surrogate may initiate the conversation with the health care team about the potential quality of life; or the health care team may initiate the conversation with the surrogate about the potential medical outcome.

Whoever initiates the conversation, the result is the same. The surrogate is able to exit the back-and-forth nature of the connection between the personal domain and the intensive care environment domain and move into the decision domain.

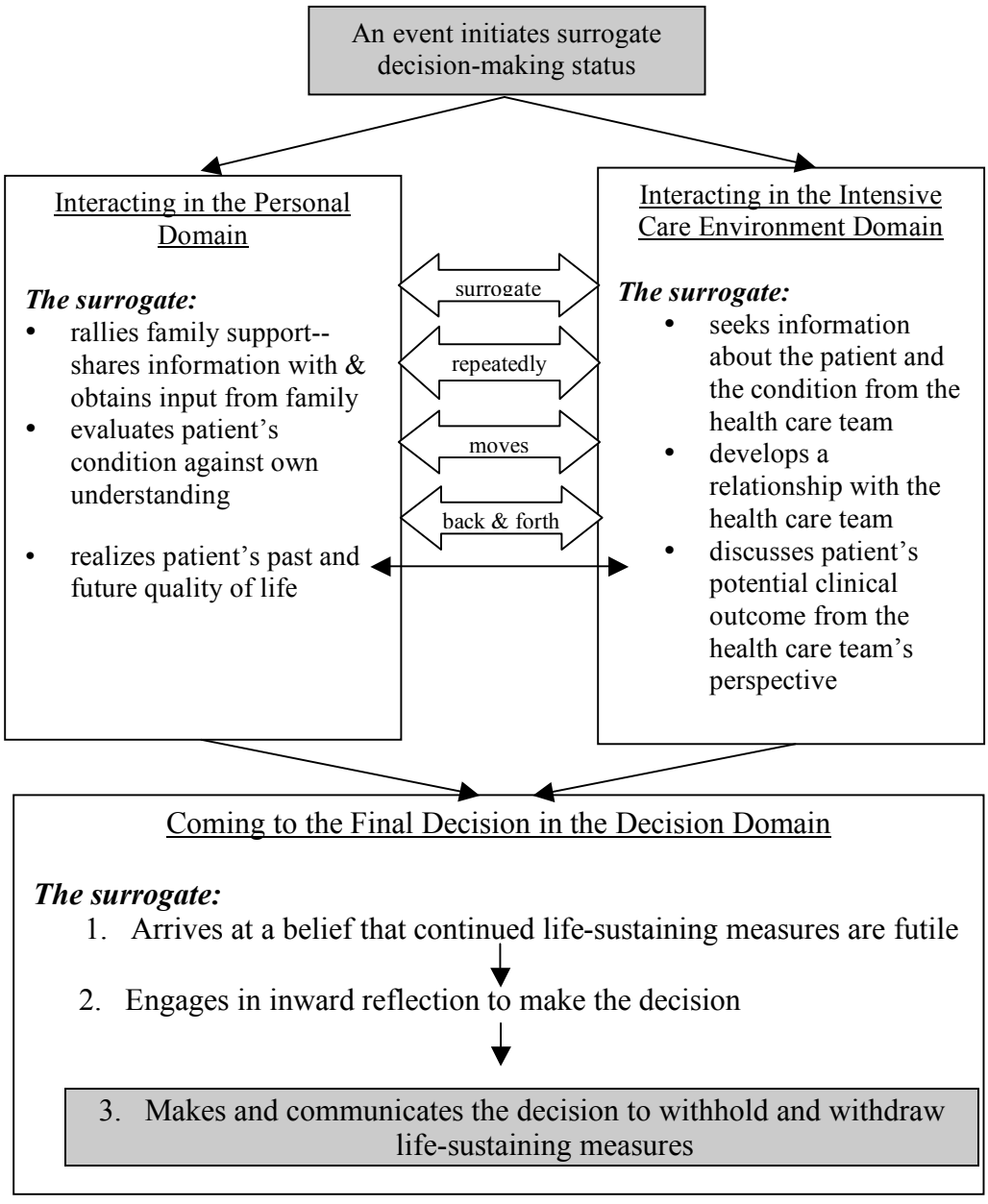
Interacting in the Intensive Care Environment Domain

Surrogates repeatedly move back and forth between the personal domain and the intensive care environment domain. As the primary interaction in the intensive care domain, surrogates obtain information about the patient's condition or status from the health care team. Surrogates express the confusing nature of conflicting or changing opinions, particularly from the physicians. Members of the health care team frequently use jargon, which can lead to further confusion related to the patient's status and potential for recovery.

Surrogates develop a relationship with the health care team while the patient is in the intensive care environment. Surrogates who were able to participate in all of the treatment decisions for their loved one expressed a sense of a more trusting relationship with the health care team. However, this relationship is often characterized as unfavorable, with surrogates reporting exchanges of animosity between the surrogate and members of the health care team, particularly physicians. Nurses are generally seen as supportive to the surrogate and are often asked to translate complicated information for

Figure 4.2

The Process Used by Surrogate Decision Makers to Withhold and Withdraw Life-sustaining Measures in a Catholic Intensive Care Environment



the surrogate.

Once the health care team confirms the potential medical outcome for the patient, surrogates are able to weigh this information against the potential quality of life in the personal domain. This intersection of the intensive care environment domain and the personal domain propels the surrogate out of this iterative phase and into the decision domain.

Coming to the Final Decision in the Decision Domain

Once the surrogate is in the decision domain, the surrogate arrives at a new belief that continued life-sustaining measures are futile. Even when the surrogate believes in the futile nature of the continued life-sustaining measures, the surrogate is plagued with feelings of guilt and uncertainty about the decision to withhold and withdraw. Surrogates say they experience a sense of unreality about the realization that the decision for the patient needs to be made. The surrogate then retreats into his or her own mind to weigh all of the information about the situation and the patient. This inward reflection allows the surrogate actually to come to the decision to withhold and withdraw life-sustaining measures. This decision is then communicated to the health care team to be carried out, and the life-sustaining measure is withdrawn or withheld. Some surrogates communicate the treatment decision to the loved one, and some do not. Similarly, some surrogates remain with the patient until the death, and some do not.

This theory expresses the decision-making process of the surrogates involved in this study. This theory of the decision-making process is intended to inform health care teams who work with surrogates and the terminally ill in intensive care environments.

Through the understanding of this process, health care teams can be better informed and more completely support surrogates who must face these difficult decisions.

SUMMARY

This chapter has presented the results of a grounded theory study to determine the process used by surrogate decision makers who had made the decision to withhold and withdraw life-sustaining measures in a Catholic intensive care environment. Analysis of the surrogates' stories revealed a process that is expressed in three domains and nine themes. Many steps in the surrogate's decision-making process are inter-related, and this interaction in the domains has been explained. Visual representation of this process is presented in a model (see Figure 4.2).

To summarize, surrogates shared stories of their decision-making process about the withholding and withdrawing of life-sustaining measures for an incompetent patient while in a Catholic intensive care environment. This chapter presented an analysis of the themes that emerged from the data and presented the themes in model format. Chapter 5 will discuss the findings and their implications for practice and future research. Additionally, methodological issues will be presented.

CHAPTER 5

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

The purpose of this chapter is to provide the reader with a summary of the study, present the study's conclusions, and make recommendations for nursing practice and future research in this area. The final step in the grounded theory process is related to publication of the results. Strauss and Corbin state that researchers must share their study findings, as "no professional body of knowledge can be accumulated, nor can its implications for practice and theory be usefully developed, without the fulfillment of this obligation" (1998, p. 246-247). Presenting the grounded theory study results will contribute to the body of nursing knowledge in this area.

OVERVIEW OF THE STUDY

The purpose of this grounded theory study was to understand the process used by surrogate decision makers who made the decision to withhold and withdraw life-sustaining measures while in an intensive care environment. All of the surrogates interviewed made the decision for a loved one, such as a spouse, parent, or sibling. The study consisted of interviewing surrogates who had made decisions to withhold and withdraw interventions from loved ones while the patients were in an intensive care. All of the patients died at or close to the time of the decision to withhold and withdraw life-sustaining measures. The surrogates were interviewed no sooner than three months and not longer than twelve months following the death of the patient.

The use of grounded theory methodology allowed for the use of an unstructured interview schedule, comprised of loosely defined questions, to obtain responses from

study participants. The schedule consisted of questions that were intended to identify the process used by the surrogate decision-makers who made the decision to withhold and withdraw life-sustaining measures. The study participants were interviewed using an active interview technique (Holstein & Gubrium, 1995), which encourages the researcher to guide the participant through a series of questions that will elicit the desired information. This questioning technique allowed the researcher to focus the questions as the interview unfolded and to probe for issues that would best inform the research. While the interviews were designed to be flexible, the researcher was necessarily required to devise a questioning schedule with which to initiate the research process. A copy of this initial interview schedule is included in the appendix (See Appendix D). It illustrates the type of questions asked of the participants but does not represent the full range of questions directed to the study participants.

The research variable – namely, the process used by surrogate decision makers to withhold and withdraw life-sustaining measures – was investigated through an analysis of 17 face-to-face interviews, which were conducted by the researcher in the central Texas area. Study participants were solicited through recruitment letters sent by volunteers at a local Catholic health care organization. The Catholic health care organization identified patients admitted to one of the many intensive care environments within their health care system who had life-sustaining measure withheld or withdrawn. These patients were either incapable or became incapable of participating in their own health care decisions, and surrogates were sought to make decisions for them. Recruitment letters were then sent to the surrogates who had made decisions on behalf of incompetent patients.

Potential study participants were invited to participate in the study through a detailed letter explaining the study and its intent.

A recruitment packet was mailed to the potential study participants. This packet included a one-page cover letter from the intensive care managers introducing the researcher and assuring the potential study participant that no personal information about the participant or the now deceased patient had been shared with the researcher. This introductory section of the cover letter was followed by a message from the researcher. The second and third pages of the cover letter, which came from the researcher, explained the study and how to contact the researcher by telephone, e-mail, and U. S. mail. The packet included a self addressed stamped envelope and a reply card. The reply card could be completed by the interested study participant. The researcher did not know who received letters from the hospital system, and the hospital system did not know who had responded to the research query. The confidentiality of the potential study participants was thus protected.

Veatch's (1984) reasonableness standard provided the conceptual framework for the study. Surrogates were seen as valid decision makers for incompetent patients, provided that they had acted in a reasonable fashion and without spurious intent toward the patient in an intensive care environment. Additionally, the surrogate must have been appointed by the patient or designated by appropriate legislation (Tex. Health & Safety Code Ann. §166.046, (Vernon, 1999)).

Grounded theory provided the qualitative research analysis methodology. The surrogates' stories were interpreted using grounded theory methodology to allow for the

emergence of themes consistent with the decision-making process used by the surrogates to withhold and withdraw life-sustaining measures from a patient in the intensive care environment. Trustworthiness of the data analysis was obtained using feedback from several of the interested participants. Preliminary results were mailed to the study participants who had expressed a desire to participate in this phase of the study preparation. These study participants were encouraged to share their opinions about the study results with the researcher. All participants agreed with the researcher's presentation of the results and the model used to express the results.

DISCUSSION OF RESULTS

The stories shared with the researcher by the surrogates were both poignant and informative. These 17 surrogates shared a vast array of experiences that can be used to inform the health care profession about to best to guide future surrogates. However, it should be remembered that the research data consists exclusively of the surrogate's remembrances of the decisions to withhold and withdraw life sustaining measures for a loved one. The ability to recall these decisions accurately was not questioned by the researcher. The results are reflective of the surrogates' understanding of themselves and their decision-making process.

Once individuals became surrogates – generally after a sudden precipitating event - they followed a unique decision-making process in order to determine whether to withhold and withdraw life-sustaining measures from an incompetent patient in the intensive care. Surrogates moved iteratively between the known, familiar personal domain and the often intimidating, unfamiliar intensive care domain. Information

gathering and processing was done by the surrogate until the surrogate realized the futile nature of continuing life-sustaining measures. The surrogate then moved into the decision domain and arrived at a decision to withhold and withdraw life-sustaining measures. This decision was communicated to the health care team, and the surrogate said his or her good-byes to the patient. The following is a discussion of the theory developed from the themes that emerged during interviews with the surrogates.

Interacting in the Personal Domain

Interactions in the personal domain were dominated by efforts to rally family for support and by discussion with friends and family of the best course of action for the patient. Surrogates found this part of the domain particularly useful to them, in that they were able to obtain family support and agreement and come to understand the futile nature of the patient's condition. Not only did the interactions in this domain provide the surrogate with much-needed encouragement, they also helped families to stay informed of decisions regarding the treatment options for the patient and the eventuality of futile care. All of the surrogates in this study were able to come to consensus with family members regarding the dying patient. Several surrogates spoke of the need to avoid disagreement so as to avoid later feelings of animosity and uncertainty in their decision-making.

The study results are consistent with Pierce's (1999) finding that end-of-life care can be improved by the involvement of family members. Families as a decision-making unit have been studied several times (Tilden, Tolle, et al., 1999; Tilden, Tolle, et al., 2001; Hiltunen, Medich, et al., 1999; Swigart, Lidz, et al., 1996; Swigart, 1994). The

results of this study are consistent with other researchers' conclusions that families as decision-making units make choices for an incompetent patient more readily than individual surrogates without family support.

Another theme within the personal domain was the surrogate's evaluation of the patient's condition against what was seen and what was understood by the surrogate. Surrogates carried out their evaluations with such issues in mind as burdens associated with treatments, preconceived limits on treatment, and the patients' and surrogates' pre-existing plans for end-of-life care. Surrogates were best able to evaluate the critical nature of patients' conditions once they understood that every possible chance for recovery had been offered to the patients.

These results are consistent with Meeker's finding (2004) that surrogates "acted for" their loved ones after "brokering information" and "working with [their] families" The results are also consistent with work done by Tilden, Tolle, Nelson, Thompson, and Eggman (1999} and by Swigart, Lidz, et al. (1996). These studies suggested that families often vacillated in their decision to forego life extending treatments until they were able to come to terms with the burden being experienced by the patient.

The last part of the personal domain involved the surrogate considering the patient's quality of life if treatment were to be initiated or continue. For all of the surrogates in the study, this theme emerged as a consistent end point in the personal domain. This part of the process gave the surrogates clues about the need to withhold and withdraw life-sustaining measures. Surrogates often wanted their loved ones to be able to return to their pre-hospital status. The surrogate who told the story of her mother, who

was in a nursing home prior to admission to the hospital, is a good example. Even though the patient was not active and had suffered one stroke, the surrogate wanted her mother to be able to return to her long-term care residence. Once the surrogate determined that her mother would not be able to attain this pre-hospital state, the surrogate began to move in the direction of withholding and withdrawing life-sustaining measures.

Once surrogates developed an understanding of the future quality of life for their loved ones, they often validated their perceptions with the health care team. While the health care team may have attempted to discuss potential medical outcomes for patients prior to this time, surrogates were only able to attend to the team members after gaining insight on their own into their loved ones' probable medical outcomes and potential future quality of life.

This finding is consistent with Hiltunen, Medich, Chase, Peterson and Forrow's (1999) observation that families reach a turning point in the decision-making process, and that reaching this turning point "requires time, work, and energy for the decision-makers" (p129). Tilden, et al. (1999) published a similar finding, concluding that families are often able to face the question of forgoing life extending treatments only after their health care teams raise the issue, or the patients have undergone a significant change in their condition. The current study results are consistent as well with Jacob's (1998) discovery that a surrogate will attend to various cues in order to ascertain a patient's condition, and that the surrogate uses these cues to make a decision to forgo life-sustaining measures. Finally, this study's findings are similar to those of Swigart (1996), whose work demonstrated that families were able to make decisions about withholding and

withdrawing life-sustaining treatments once they had come to the realization that the patients themselves would not want to continue these measures.

Interacting in the Intensive Care Environment Domain

Interacting in the intensive care environment domain was distinguished by the surrogates seeking information about the patient from members of the health care team. Relationships that were not always amicable developed between the surrogates and the members of the health care team. However, eventually the surrogates learned to trust the health care team members. Surrogates reached a point in the decision-making process where they could accept information from the health care team members about issues, such as the futility of continued care.

Within this domain, surrogates spoke consistently about needing information in order to make a decision regarding their loved ones. Surrogates wanted regular reports and updates on the patients in much the same way that health care providers expect to receive information from their colleagues at the beginning of each new work shift. This felt need to gather detailed information has been identified by several authors as a central element of the surrogate's decision-making process (Baggs & Schmitt, 2000; Hiltunen, Medich, et al., 1999; Tilden, et al., 2001). Jacob found that surrogates "gathered the information they needed to make the decisions [and] informants described a variety of data-seeking behaviors" (1998, p. 33). Swigart, et al. (1996) also found that families wanted patient information and attempted to understand the critical nature of the terminal illness.

However, none of the aforementioned studies makes reference to the idea that surrogates might describe their need for information as "chasing doctors," and none seemed to observe that surrogates go to great lengths to obtain information. A possible exception to this trend in the literature is one investigation conducted by Norton, et al. (2003), which suggested that surrogates who experienced difficulty with clinicians in the transition to palliative care also report a significant need for information and honesty regarding their loves ones' condition. In the current study, surrogates reported that they felt as if they were literally chasing doctors down hallways and corridors to get information. When physicians' schedules were predictable, moreover, some surrogates would go into the intensive care unit to confront physicians and demand information from them. One surrogate stated that she "demanded" a meeting with her husband's physician, because she needed to know what the medical team knew in order to make an informed decision for her husband.

Surrogates also expressed opinions about the kind and type of language that the health care teams used when communicating information about patients. This language often was received as confusing jargon to surrogates and further complicated decision-making. In this domain, surrogates spoke too of the conflicting medical opinions they heard from physicians, which added additional confusion to the decision-making process. Most surrogates, however, asked question of physicians and nurses to clarify what was being said about the patient in intensive care. These results are consistent with Cohen-Almagor's (2000) finding that physicians use language for the sake of convenience in end-of-life situations, often causing surrogates to agree to unwanted treatment. Crawley,

et al. (2002) have posited that a lack of culturally competent language is responsible for instances in which treatment decisions are made that are not in keeping with the patient's or surrogate's goals for the end of life.

Within this domain, the surrogate's relationship with the health care team also played a role in the decision-making process. Surrogates uniformly reported that relationships developed between themselves and the health care team while their loved ones were in the intensive care environment. These relationships often included significant enmity, which stemmed from the surrogates perceptions of how physicians communicated with them and other family members. Surrogates often described physicians as condescending or outright rude in their approach, particularly when no prior relationships existed between the physicians, patients, surrogates, and families. Surrogates wanted to work with health care team members in order to come to a satisfactory decision about end-of-life care, but when animosity was present, surrogates were forced to deal with layers of unanticipated emotion that interfered with the process.

This finding is consistent with the conclusions of other studies. In an investigation conducted by Tilden, et al. (1999), for example, it was discovered that families often thought physicians were too tentative in their descriptions of patients' prognoses; this led to decisional confusion for the surrogates. Jacob (1998) also found that families experience a need for involvement from the health care team when they are attempting to make treatment decisions. Jacob's conclusions are consistent with the current study's results, which indicate that establishing a relationship with the health care team is vital to understanding and accepting the necessity of a decision to withhold and withdraw life-

sustaining measures. Additionally, a study conducted by Norton suggested that ease of decision-making was dependent upon the degree of harmony enjoyed by the surrogate with the health care team. Finally, Norton, et al.'s (2003) study of surrogates who experienced conflict with members of the health care team during the decision-making process revealed that effective communication could greatly reduce the chances of disagreement over major decisions between surrogates and health care professionals.

While nurses were not exempt from developing a less than amicable relationship with surrogates, most nurses were viewed favorably by surrogates. Surrogates felt that nurses were able to translate complicated medical information into meaningful language, and they regarded nurses as kind and encouraging. Nurses reportedly performed their duties in such a way that surrogates felt comfortable and supported. This result is consistent with Hiltunen, et al.'s finding that "nursing interventions helped in communicating information and in guiding the process of difficult decision-making" (1999, p. 131).

For all of the surrogates in the study, this last theme, in which relationship issues with the health care team predominated, emerged as a consistent end point in the intensive care environment domain. A surrogate's interaction in the intensive care environment domain concluded when the surrogate was able to accept the health care team's confirmation that, irrespective of treatment, the potential medical outcome for the patient was optimally poor or would result in death. Surrogates particularly wanted to hear some confirmation from physicians that their loved ones' conditions were irreversible or terminal. One surrogate even stated that, although he had received this

information from nurses, he needed to hear the news from the physician in charge of his father's care. This confirmation or prediction about the end of life for patients assisted surrogates in moving into the actual decision-making process necessary to authorize forgoing further treatment for patients.

This finding is consistent with Fins, et al. (1999) who found that physicians can and do accurately predict the end of life for patients approximately 75% of the time, and the presence of surrogates increases the number of do-not-resuscitate orders and comfort care plans for patients at the end of life. Jacob's work, suggests that the decision to withhold and withdraw life-sustaining measure is in large part dependent upon the quality of the relationship between surrogates, physicians, and nurses. This need for a trusting relationship with the health care team is consistent with the current research.

Coming to the Final Decision in the Decision Domain

Surrogates could only enter the decision domain after they had completed their work in the personal and intensive care environment domains. Coming to a final decision in the decision domain was accomplished by the surrogate's arriving at a new belief about the futility of care, turning inward to make the decision, and communicating the decision to the health care team. This linear part of the decision-making process was preceded by the surrogate's iterative interaction in the personal domain and the intensive care environment domain.

The first theme in the decision domain consisted of arriving at a new belief about the patient's condition. Surrogates entered the decision domain when they had arrived at a new belief about the patient and the decision that needed to be made regarding

withholding and withdrawing life-sustaining measures. It was after the surrogate was able to hear from the physicians and foresee the patient's potential future quality of life (if any) that the surrogate could undertake the process of actual decision-making. The surrogate's arrival at this new understanding with regard to the patient came about when she or he was able to integrate the health care team's information with his or her own understanding of the situation. This integration occurred only after the surrogate weighed all of the available information and predicted all potential outcomes for the surrogate.

This need to arrive at a new belief has been observed by other researchers. In a study conducted by Hiltunen, et al. (1999), for example, it was discovered that families and surrogates needed to reach a "turning point" before they could terminate burdensome treatments. In addition, Hayes' (2003) work found that surrogates were able to make decisions for incapacitated adults once they were able to assess the patient's potential quality of life and consider a variety of personally meaningful criteria, such as the meaning of death and their own spiritual beliefs.

In the next area of the decision domain, surrogates retreated into their own minds to come to their final conclusions about continued care. Before surrogates could make the actual decision to withhold and withdraw life-sustaining measure, they needed to have some variable amount of time for inward reflection on all of the information that they had received prior to this point. Each of the surrogates expressed the idea that they reflected on their own about the patient, the terminal nature of the condition, and the idea that withholding and withdrawing life-sustaining measures was a real possibility. Surrogates did not need to be physically isolated to go through this process. For example, one

surrogate stated that he was embracing his sister when this phase of the process occurred for him. While he was not alone, he was reflecting on his own about the decision to withdraw his father's ventilator.

Other researchers have commented on this phenomenon among surrogates, although they have downplayed the role of solitude at this point in the decision-making process. In a study conducted by Hiltunen, et al. (1999), for instance, surrogates were found to need time to let go of patients in intensive care environments. Specifically, they required an opportunity to understand and accept the critical, futile nature of continued aggressive care, including life-sustaining measures. Jacob also identified a moment of psychological resolution for surrogates, which she described as "looking back and going on" (1998, p. 33). Jacob's work demonstrates the need for surrogates to interact with others in a meaningful way in order to integrate the information they have received and make decisions about continued care. However, none of these researchers spoke about the surrogates' need to retreat within their own minds for reflection and decision-making.

In the last step of the decision domain, surrogates communicated the decision to withhold and withdraw life-sustaining measures to health care personnel. In the interviews, they reported using a variety of strategies to convey this information. Some surrogates were blunt and actually said, "No more treatment," to members of the health care team. Other surrogates were less explicit in their communications and used euphemisms, such as, "We can't leave him like that".

Little discussion about how surrogates communicate their decisions to withhold and withdraw life-sustaining measures exists in the literature. Hiltunen, et al. (1999)

commented on surrogates' experiences of "vacillation" and "decision reversals" at the end of their loves ones' lives, and Tilden, et al. (1999) observed that surrogates were willing to take some action in the direction of withholding and withdrawing life sustaining measures soon after they had made their final decisions. According to Tilden, et al, "Once having faced the question, families generally were ready to act, and most made the decision to withdraw treatment within 24 hours after the question was called [by the health care team]" (p. 436).

Summary

In the current study, it was observed that a clear process was commonly used by the seventeen surrogates charged with making the decision to withhold and withdraw life-sustaining measures from incompetent patients in intensive care. The contents of this process were revealed through in-depth interviews. These interviews allowed for the emergence of themes, which could then be identified as members of clusters within broader representative domains. Surrogates moved back and forth between the personal domain and the intensive care environment domain until they realized the futile condition of the patients. Once surrogates had come to this realization, they quickly moved into the decision domain, at which point the actual decision was made and communicated to the health care team.

The domains have been represented here as a theory accompanied by a visual model. The theory will ultimately guide health care professionals, so that they can understand and support surrogates making the decision to withhold and withdraw life-sustaining measure from incompetent patients in intensive care.

INFLUENCE OF THE CATHOLIC CHURCH

All of the study subjects were recruited with the assistance of a local Catholic hospital system. The Catholic Church exerts influence upon the management and delivery of care for its patients in this hospital system through the Ethical and Religious Directive for Catholic Health Care Services (United States Conference of Catholic Bishops, 2001). The study goal was to understand the process used by surrogate decision makers who have made the decision to withhold and withdraw life-sustaining measures specifically in a Catholic intensive care environment.

An interview schedule was prepared to uncover the details that govern this process. Use of grounded theory methodology calls for the researcher to pay attention to the context surrounding study subjects, because it is believed that this context in part determines the process in question (Strauss & Corbin, 1998). Therefore, the study included questions designed to ascertain if there was an influence of the teachings of the Catholic Church upon surrogates and their decisions to withhold and withdraw life sustaining measures. Additionally, the study sought to determine if surrogates made a conscious choice to utilize Catholic managed hospitals and if they would choose to attend this type of hospital in the future.

All of the surrogates in this study denied that they specifically elected to receive care at a Catholic hospital, and only one surrogate stated that she would choose to go to a Catholic hospital in the future. None of the surrogates in this study felt that the teachings of the Catholic Church (i.e., the Ethical and Religious Directives) had any influence upon decision-making. Only two patients and one of the surrogates were Catholic. Several

surrogates stated that they drew on their own religious or spiritual beliefs to assist them with the decision forgo treatment for a loved one. A typical example of the surrogates' responses is reflected by one surrogate who made a decision regarding life-sustaining measures for her sister. This surrogate stated that she drew on her own religious beliefs to accept that her sister was going to die and eventually be in a better place without pain. These responses represent striking results and are true to the study participants. These results may not provide a picture of patients and surrogates who receive care in other Catholic intensive care environments.

The typical response was very much like that of Surrogate 2. When asked by the researcher if she chose to go to a Catholic managed hospital, she replied,

> I'd go to where I felt the best care was. However in this case, the Catholic hospital was the one where our insurance sent us to. [Laugh]. And I think also it might, it may have been the hospital that the oncologist used. That also has to do with it.

Surrogates did not choose to use the services of a Catholic managed health care system on the basis of the system's religious affiliation. Instead, insurance or a prior relationship with the hospital in question tended to dictate the choice. Some patients were taken to a hospital within the Catholic hospital system, because that hospital happened also to be the regional trauma center and therefore received by default most emergent admissions. Surrogate 9, for example, stated that she had no choice in the selection of a hospital for her husband's care: "Um, um. He… that's just where they flew him." Surrogate 3 reported that his wife became a patient within the Catholic managed hospital system

because the couple had a long-standing relationship with the hospital that had nothing to do with its religious affiliation. He remarked in response to a question about the importance of receiving care from a Catholic institution,

> No. No, that didn't matter. That didn't matter. We've always gone to [name of hospital] when it's the right time. We've been there fifty years. And just like I guess kind of stuck on us, you know. Just go to [name of hospital], because you know there was times where that's the only place we could go.

In general, then, selection of care for a critically ill person does not seem to be dependent upon a belief in the teachings of the Catholic Church or upon the management of the hospital system by the Catholic Church.

This study's findings are not consistent with those other researchers in the area of religious and spiritual influence at the end of life. Hamel and Lysaught (1994) for example, found that religious beliefs have an impact on choices regarding palliative care. The authors identified several ways in which spirituality can affect treatment decisions for the terminally ill. They concluded that religious beliefs "can and do affect palliative care decisions by forming the moral character of religiously oriented (and even some non-religiously and former religiously oriented) patients, family members, and caregivers" (p. 65). While the context surrounding Hamel and Lysaught's study differs from that of the current study, their work suggests that religious influences play a part in treatment choices made at the end of life. In addition, Albaugh (2003) conducted a study demonstrating that spirituality affects Christian patients' hospital courses during life threatening illnesses. Albaugh's investigation indicates that Christian patients draw on

their spiritual beliefs (including belief in a higher power or God) for strength. The study participants in Albaugh's study, manifested higher levels of comfort, trust in the health care system, and meaning in their lives as a result of their beliefs. While the current study focused on a different research question and recruited a different participant population, both projects reveal that patients and surrogates alike draw on spiritual and religious beliefs to assist them in coping with illness and making difficult health care decisions.

However, as with all research, this is not a static state in which believers and non-believers choose a set of supportive techniques from an esoteric tool chest. The current state of the world (especially regarding end-of-life issues) will always influence people's choices regarding life-sustaining measures. Perhaps nowhere is this truer than in the American Catholic Church. The faithful in the health care professions are guided by the Ethical and Religious Directives for Catholic Health Care Services (ERD) (United States Conference of Catholic Bishops, 2001), which were recently revised. This document provides guidance to Catholic health care providers about end-of-life care, as well as other common health issues. While the ERD contains a wealth of information, it is not designed to serve as a blueprint to the faithful regarding which treatments should or should not be undertaken to preserve or promote life. Attempts to interpret the ERD and other Catholic doctrine regarding end-of-life care have confounded rather than clarified the Church's position regarding several important life-sustaining measures.

Unfortunately, the Pontifical head of the Catholic Church, H. H. Pope John Paul II, has contributed to the cloudiness surrounding end-of-life care decisions. In April, 2004, Pope John-Paul II issued a Papal Allocution related to artificial hydration and

nutrition for the vulnerable and incompetent patient. In the Allocution, the Pontiff described the manner in which health care providers should care for those who cannot speak for themselves and who have not made their intentions known (via surrogates or family) regarding end-of-life care. The Pope admonished health care providers not to make assumptions about what constitutes a high quality of life for patients. Rather, the Pope reaffirmed the idea that artificial hydration and nutrition should be provided to those in a persistent vegetative state (PVS) as a first resort.

While the Papal Allocution does not appear to change 500 years of Catholic theology, some conservative factions within the Church have speculated that the Allocution does in fact represent a less-liberal interpretation of the Church's traditionally stance regarding end-of-life care. Some see this latest statement by the Pontiff as vitalistic or as reversing the ERD to state that it is always necessary to preserve life regardless of the emotional, physical or financial cost (Shannon & Walter, 2004). The Pontiff did not in fact reverse the current doctrine contained in the ERD, but confusion about end-of-life care continues to exist within the Catholic community.

American Catholic ethicists O'Brien, Slosar, and Tersigni (2004) examined the Allocution in great detail, and they concluded that the Pope reaffirmed hydration and nutrition as preferred forms of treatment but not at the expense of patients' stated wishes. The Pope's statement is in keeping with accepted legislation related to end-of-life care, inasmuch as the Pope dictated that a patient's wishes should be communicated to a legitimate surrogate who should ideally have documentation detailing the patient's wishes regarding end-of-life care. Moreover, the Allocution is directed at health care

providers and not necessarily at the Catholic faithful. The authors comment on this limitation,

> Insofar as the [Allocution] explicitly speaks to health-care professional and society, and affirms for them an obligation from which *they* cannot exempt *themselves*, it does not appear to be directly addressing the specific obligations of patients regarding the use of life-sustaining treatments. Simply because a professionals have a moral duty to offer a particular form of care or treatment does not itself imply that a patient has a duty in all cased to accept that form of care of treatment. (O'Brien, Slosar, & Tersigni, 2004, p.504)

Despite the narrow focus of the Allocution, its ambiguities have generated considerable discussion within the Catholic lay press. Winfield (2004), for example, sensationalized the Pontiff's statement and called removal of a feeding tube "euthanasia by omission" (n.p.). While the Allocution did indeed use these words, Winfield took them out of context and created further confusion among the faithful, who are attempting to adhere strictly to Catholic teachings. If read in the context of the Allocution, the words "euthanasia by omission" cautioned health care providers not to make a judgment about an individual's life without knowledge of that person's wishes or values.

Indeed, such confusion has spawned the creation of a lay Catholic website dedicated to the vegetative state (Winfield, 2004), which details conservative views regarding PVS and argues that Catholics should preserve life at all costs. Moderate members of the ethics community within the Catholic Church have also tried to clarify what the Allocution might mean for American Catholics. The National Center for Ethics

in Health Care (2004), for example, endorses the ERD's position that hydration and nutrition should be used presumptively, but not at the cost of placing excessive physical, emotional, or financial burdens on patients and their families.

The ambiguity surrounding whether to preserve life at all costs is not a new issue among the Catholic faithful and clergy. According to Rigali (2000), for instance, the Archbishop of St. Louis intentionally left the issue of necessary treatments at the end of life open to interpretation when he issued a press release in response to the previous edition of the ERD (United States Conference of Catholic Bishops, 1995). Moreover, conservative authors, such as Province (2003), have attempted to reframe the idea of withholding and withdrawing artificial hydration and nutrition as tantamount to murder. Province writes,

> The evaluation of probabilities, founded on waning hopes for recovery when the vegetative state is prolonged beyond a year, cannot ethically justify the cessation or interruption of *minimal care* for the patient, including nutrition and hydration. Death by starvation or dehydration is, in fact, the only possible outcome as a result of their withdrawal. In this sense it ends up becoming, if done knowingly and willingly, true and proper euthanasia by omission (n.p.).

The Pope's recent Allocution (2004) uses words similar to Province's in its statements regarding PVS. While the language in both instances is certainly strong, many authors feel that it represents no more than a simple reaffirmation of existing Catholic doctrine related to artificial hydration and nutrition. What the Pontiff appears to have communicated, then, albeit in a somewhat confusing manner, is that health care

professionals should provide artificial hydration and nutrition presumptively to patients in PVS; but this provision is not an absolute mandate.

The surrogates in this study made their decision regarding the withholding and withdrawing of life-sustaining measures prior to the issuance of the Allocution. This begs the question; could the Papal Allocution have an impact on future surrogate decision-making? It has been suggested in the popular American Catholic press that the Pontiff is indeed requiring the faithful to endure burdensome treatments even at the expense of their wishes (Kopaczynski, 2004). This interpretation could lead to the slippery slope phenomenon, in which the acceptance of exceptions and narrow inclusions to a rule eventually lead to a blurring of its true meaning. Slippery slope arguments, because they introduce a novel class of distinctions to a rule, tend to produce interpretations of the rule that were never intended.

What are health care providers required to do for those who are unable to participate in their health care decisions, either permanently or temporarily? Will the Papal Allocution have an effect on patients with conditions similar to PVS, such as profound mental retardation or dementia? Should Catholics interpret the Allocution's statements regarding those who are incompetent in broad or narrow terms? (Shannon & Walter, 2004). For example, if the Church directs health care providers who operate under the auspices of the ERD to provide artificial hydration and nutrition to those in a permanent vegetative state, should it be assumed that the Church intends these providers to behave similarly when treating patients with cancer or heart disease, who also may not be able to voice their opinions regarding life-sustaining measures? The slippery slope

argument might be invoked so that these other patient conditions, which were never remarked upon in the Papal Allocution, would require similar treatment.

Given that the Allocution was issued after the surrogates in this study made decisions regarding withholding and withdrawing of life-sustaining measure, the surrogates who were interviewed were not affected by the Pontiff's message. However, all of the surrogates in the study refuted the idea that the teachings of the Catholic Church had any affect upon their decision-making. Additionally, the surrogates in this study did not choose a Catholic managed hospital nor would they necessarily choose this type of hospital (Catholic) in the future. Choices related to location of care were driven by more practical considerations such as physician hospital preferences, insurance reimbursement contracts with the hospital, or community directives for the choice of emergency services.

CONCEPTUAL ORIENTATION

The study was guided by Veatch's (1984) guardian reasonableness standard. Veatch used the term *guardian* to identify those persons in a position to make a decision for another, such as surrogates who are called upon to make a decision for those incapable of participating in their own health-care-making decisions. The study findings are consistent with Penticuff's (1988) article in which surrogates were found to be appropriate decision-makers. However, Penticuff's work involved parents who made decisions for their children and as such may not represent a true comparison of the study findings.

Veatch described surrogates as those who are bonded and those who are non-bonded (Veatch, 1984; Penticuff, 1988). Bonded guardians are those persons with whom

the patient had a prior relationship and are most often a family member or a close friend. Non-bonded guardians are those persons, such as court appointed guardians, who had no prior relationship with the patient. Both labels for the types of guardians apply to the relationship with the patient before the time in which the decision regarding withholding or withdrawing of medical treatments must be made. All of the surrogates in this study were bonded guardians. All of the surrogates interviewed were either selected by the patient or were legislatively designated under the Texas Health and Safety Code (Tex. Health & Safety Code Ann. §166.046, (Vernon, 1999)) such as a spouse or adult child of an incompetent adult.

Bonded guardians often have an advantage over other guardians in that a relationship exists with the patient prior to the time in which surrogacy was necessary. For instance, when the wishes of the incompetent patient are known prior to the time in which the patient became incompetent, then the guardian may make a substituted judgment decision based upon his or her knowledge of the patient. However, when the guardian does not know the wishes of the patient prior to incompetence, then the best-interest standard should apply (Veatch, 1984, Penticuff, 1989).

Surrogates in this study used both standards, which is consistent with Veatch's (1984) reasonableness standard. Those surrogates who knew what the dying patient wanted used the substituted judgment and those who did not know what the patient wanted used the best-interest standard to make their decisions regarding life-sustaining treatment. However, in most instances where the surrogate knew that the dying patient did not want extraordinary means to sustain his or her life, the surrogate often agreed to

the use of invasive life-sustaining measures, only later to decide to withdraw these same treatments.

This finding is also consistent with Sulmasy and colleagues' (1998) work. In this study, terminally ill patients were found to agree with a surrogate's substituted judgment even when that surrogate's decision might have been contrary to the patient's known wishes related to forgoing life support. Sulmasy and collegues' work makes the additional point that patients would prefer the surrogate's incorrect substituted judgment over the same decision that might have been made by the health care team.

Additionally, the study results are consistent with Terry and colleague's work (1999). In this study, terminally patients and surrogates were asked to rank in order the desirability of life-prolonging interventions. Surrogates were found not to be able to predict a patient's preferences accurately. However, it was hypothesized in this study that patients would prefer the surrogate to make an inaccurate choice based upon the premise of substituted judgment for the patient rather than have the health care team apply the best interest standard.

The use of Veatch's (1984) guardian reasonableness standard was an appropriate framework for this study. None of the study participants described themselves as guardians per se; they did however, see themselves as the person who made the decision for the dying patient and often expressed their decision in terms of the best interest standard or the substituted judgment standard. However, surrogates often desired extensive life-prolonging procedures before making a decision to withhold and withdraw

life sustaining measures and basing that decision in what can be viewed as Veatch's (1984) reasonableness standard.

Veatch's (1984) guardian reasonableness standard may help health care providers to support surrogates better. Attempting invasive life-sustaining measures, even when the patient's wishes are contrary to this fact, is a part of the surrogate's decision-making process. This desire for the health care team to "do everything" was not done with malicious intent. It was motivated by the need to assuage feelings of uncertainty and guilt that most often accompanied decisions as to withhold and withdraw life-sustaining measures. This therapeutic trial of invasive therapies allowed the surrogates to reach a decision consistent with what Veatch would call the reasonableness standard.

METHODOLOGY

The recruitment process used in this study was successful. The health care agency participated in identifying the surrogates and enlisted volunteer staff nurses to assist with mailing the recruitment letters. This inclusion of the agency gave the hospital system and the staff nurses some sense of participation, if not ownership. This tie between the service agency and the academic agency was a good partnership and should be encouraged whenever possible.

Recruitment mailings were done in two rounds. The first mailing was based on deaths that occurred in the intensive care environments during the highest death months for the health care system. This mailing for the months of October, November, and December, 2003 yielded 7 participants out of 120 mailings. The remaining 10 participants responded from 78 pieces of mail based on deaths during January, February,

and March, 2004. A total of 6 letters were returned to the health care agency for a variety of reasons. Most of the returned mail was due to an incorrect address for the addressee. The researcher did not view this as the health care agency's nor the volunteer nurses' fault. Given the mobile nature of our society, it was assumed that these addresses were no longer valid for the addressee but were valid at the time of the surrogate's time in the intensive care environment.

Volunteer staff nurses were recruited to assist with the mailing process. As the researcher could not know who was to receive a letter, the health care agency's intensive care managers selected two staff nurses who were to receive acknowledgment for their clinical ladder promotion portfolios. This reduced the financial burden on the researcher and the agency. The staff nurses were given a computer listing of all surrogates for patients who died in the intensive care environments during the designated months. Excluded from the mailings were surrogates for all neonatal, pediatric, and trauma services patients. The volunteer staff nurses reviewed the patient's medical record for any additional or more current information regarding the surrogate's name and address. This record review assured that any change in information regarding the surrogate's name and address was as correct as possible prior to mailing a recruitment letter/packet. The volunteer staff nurses addressed letters directly to the surrogate by title, first and last name, and address.

Seventeen respondents were elicited through the mailing of 198 letters resulting in a 4.22% response rate. This represents a good response rate given that the hospital system's experience with solicitation for research with intensive care subjects has

historically been 1% (T. Conner, personal communication, September 15, 2004). This response rate may in part be due to the fact that the researcher was based outside the health care system, and the researcher guaranteed confidentiality and anonymity to all potential participants. This protection of potential study participants' information was outlined in the original recruitment letter and was again reviewed with the potential study participants at the time of signing informed consent.

Three participants chose to respond via e-mail. Three surrogates chose to use the telephone to make initial contact with the researcher. Most of the surrogates chose to respond through the use of a provided reply card in a postage-paid envelope. The envelope was pre-addressed to the researcher's post office box, and the participants were instructed not to include any identifying information such as a return address on the envelope. In the original recruitment letter, the study participants were asked to provide the best time and phone number to contact the participants. This information was written by the participant on the reply card and then mailed to the researcher. This may have yielded more participation, as the study subjects were able to designate the best-suited time to be contacted by phone. In this way, the participants had control over when and where the researcher would be in contact.

It is unknown how the response rate for this study compares to other grounded theory studies of surrogates or end-of-life issues. However, other authors have published with small numbers dealing with similar subject matter. Jeffers (1998) studied 11 surrogates with the phenomenological approach. Norton's work (1999) used grounded theory methodology to examine 20 participants who reconciled decisions near the end of

life for a loved one. Swigart's work (1994) also used grounded theory methodology to examine 16 families who were involved in decisions for a loved one. This sample size of this study involving 17 surrogates is consistent with other qualitative grounded theory studies involving surrogates and families who must make decisions for an incompetent patient. Given the nature of the study topic, it is not unusual for smaller number of respondents to reply to studies of this nature.

CRITIQUE OF THE THEORY

Walker and Avant (2005) provide researchers with a systematic method for theory analysis and critique. They describe the steps involved in theory analysis as having six steps:

> (1) Identify the origins of the theory, (2) examine the meaning of the theory, (3) analyze the logical adequacy of the theory, (4) determine the usefulness of the theory, (5) define the degree of generalizability and parsimony of the theory, and (6) determine the testability of the theory. (p. 162)

The following is a section developed using the steps as outlined above from the work of Walker and Avant (2005).

Origins: The theorist (or researcher) should delineate whether the theory was developed from deductive or inductive reasoning and if there were underlying assumptions prior to the research (Walker and Avant, 2005). The research study was developed out of the researcher's clinical background. In caring for patients and surrogates who were making decisions regarding withholding and withdrawing of life-sustaining measures, the researcher began to question if there was a unique surrogate

experience. The theory was developed from the data and the emergent themes as illustrated by the surrogates' stories. Additionally, the researcher has disclosed the study assumptions in Chapter 1.

Meaning: The major concepts of the theory should be defined along with all the relevant terms used in the definition (Walker and Avant, 2005). Walker and Avant give possible options as to the definitions in a theory: theoretical, operational, descriptive, or no definition. The theory presented here is theoretical, which by definition requires it to be abstract. As the qualitative themes or concepts are not measurable, this portion of the theory critique is met. Additionally, the concepts are not temporally or spatially delimited. The definitions of the concepts were outlined in Chapter 1 and, where necessary for clarity, repeated in the text.

Logical Adequacy: The theory presented is predominately one of an iterative nature. Logical adequacy refers to making sense and making predictions from the theory (Walker and Avant, 2005). The theory from this study has logical adequacy in that it is presented as represented by the surrogates in the study. The stories told by surrogates were analyzed for themes that were logically grouped to represent the decision-making process. Health care providers will be able to predict how a surrogate might make a decision to withhold and withdraw life-sustaining measures based upon a comparison of this theory to actions and behaviors demonstrated by future surrogates.

Usefulness: Walker and Avant (2005) refer to the measures of a theory's usefulness as demonstrated by how helpful it is in understanding and explaining the phenomenon, and if it has made a contribution to the body of scientific knowledge. As

this is a grounded theory study, no research has been generated from the study results. However, the theory provides a structure for the explanation of the phenomenon that can be used repeatedly to describe other surrogates' decision-making processes. The theory also contributes to the body of knowledge in that little is understood about the decision-making process exclusively from the surrogate's point of view.

Generalizability: *Generalizability* is a term more associated with quantitative studies. A word that expresses similar meaning in qualitative studies is *transferability*. Polit and Hungler (1999) define this term as "A criterion for evaluating the quality of qualitative data, referring to the extent to which the findings from the data can be transferred to other settings or groups (p. 717)." The study results and theory represent the process described by this group of surrogates and may not be transferable to others in similar decision-making situations. For instance, the study setting was specific to a Catholic hospital system, and only one surrogate claimed Catholic as her religious preference. It is not known if surrogates in different types of settings or if a larger sample of Catholic surrogates would yield similar results.

The surrogates in this study are represented by mostly Caucasian, mostly educated, mostly Christian, and mostly middle to upper socioeconomic class. The transferability of the study results and the resultant theory may have limitations to surrogates who do not fall into these categories. For instance, surrogates who are of a minority status may demonstrate different results and subsequently necessitate a revision in the theory expressed herein.

Parsimony: Walker and Avant (2005) refer to the parsimonious nature of a theory as being elegant. These authors refer to the most elegant types of theories being similar to Einstein's $E=mc^2$. According to Walker and Avant, a theory is most often represented by a model or graphic representation of the concepts in the theory. This was presented in Chapter 4 (see figure 4.2) and gives the reader a visual depiction of the relationship of the concepts.

However, the model does require the reader to pay close attention to the definitions of the concepts in the theory to understand the relationships as displayed in the model. Given the complexity of the process of the surrogate's decision-making, it is not unexpected that the relationships of the concepts would also be complex. There may be other ways to display the theory in model form. Nevertheless, the model representation gives the reader a clear picture of the iterative nature of the process and the initiating and culminating events in the surrogate's decision-making process.

Testability: The theory "may yield testable hypotheses and relational statements" (Walker and Avant, 2005). The theory will generate hypotheses and as such meets this criterion for theory critique. However, a replicated study might result in a different theory if conducted with a population that is much different from the surrogates in this study. For instance, the study should be repeated with variations in the type of study site (non-religiously managed hospitals or hospitals that are not a part of a large system), type of surrogate (such as just siblings), and with only Catholic surrogates who have made a decision for Catholic patients. These variants on the study presented here may lead to a more complete understanding of the phenomenon.

Summary Comments about the Theory: Reynolds (1971) wrote: "While scientific knowledge is basically a system for description and explanation, not everything can be explained by science" (p. 3). This statement by Reynolds might be interpreted to mean that no theory is perfect. Indeed, the theory presented here is not perfect. It does however, describe the process that the 17 surrogates in this study used to make the decision to withhold and withdraw life-sustaining measures in a Catholic intensive care environment. It is a step toward better comprehension of this complex issue. The theory and model presented herein assist health care providers toward greater understanding and have contributed to the body of scientific knowledge about this phenomenon.

THE INTERVIEW

Language of the Interview

Study participants were asked to describe the process used to make the decision to withhold and withdraw life-sustaining measures for a patient in an intensive care environment. The use of the term "process" was difficult for most participants to understand because they may not have viewed the decision to withhold and withdraw life-sustaining measures as a process. During the course of the interviews, the choice of words to elicit the response was of great concern to the researcher. The research question was one regarding the process of decision making; therefore, different words were tried with different surrogates to elicit the response regarding the decision-making process.

Often the participants did not perceive making the decision to withhold and withdraw life-sustaining measures as a process at all. Some surrogates expressed their decision as "there was no other choice". Many expressed their memories of the events

surrounding the task of making the decision to remove life-sustaining measures from a loved one as a total experience in a context and not some separate event. Attempting to focus on the process involved in the subject's work was not an area to which the participants easily related. However, through questioning the surrogates in all of the interviews, a process unfolded.

Surrogates expressed their stories as part of a larger experience, and to dissect that experience into parts seemed to be counter intuitive to the surrogates' remembrances of the stories. Surrogates expressed their stories as an interconnected experience and not as a process or steps. However, the researcher did impose questions regarding "process" on the study participants' interviews and was able to evoke rich descriptions of the surrogates' experiences of the decision to withhold and withdraw life sustaining measures. Toward the end of the interview, study participants were often asked if they agreed with the researcher's understandings about what was heard during the interview. Once given the researcher's language to express the decision-making process, the participants agreed with the researcher's interpretation.

All of the participants wanted to begin the discussion about their loved one with memories about the patients. The surrogates had a need to tell the researcher about who the individual was prior to illness, and they often showed pictures of the person while they were alive. Pictures of the patients most often depicted family gatherings or other scenes in which the patient was interacting with family members.

After the first three interviews, the introductory grand tour research question was changed. Initially the question was: "Can you tell me something about what brought your

loved one to the hospital for the last time?" This grand tour question quickly changed to: "Tell me about your X (where X represents the surrogate's relationship to the deceased)." Given that most participants could not or would not enter into the discussion about withholding and withdrawing until the person was remembered for whom he or she was, this change in the questioning became a better way to ease into more detailed study questions. This change in the question allowed surrogates to remember the patient in their own way and seemed to avoid pushing the surrogate into telling the researcher about the experience before the surrogate was ready to do so.

Based upon responses from the first few surrogates, the interview schedule was also changed from questions such as: "Some people believe that there is a *process* to follow when making the decision to withhold and withdraw life-sustaining measures. Was this so for you?" The question was revised to focus on "What were the steps?" used in the decision-making process. While this came closer to the surrogates' understanding of the decision to withhold and withdraw life-sustaining measures, the idea of a step-by-step process was not true for surrogates.

To further attempt to elicit surrogates' responses regarding the process used in making the decision to withhold and withdraw life-sustaining measures for a loved in an intensive care environment, a simple imaginary task was given to the surrogates toward the end of the interview. The surrogates were asked to imagine what they would include in a letter to someone who was going through the same situation. This seemed to be more of a familiar task, and most of the participants were able to use the letter vehicle to tell about process steps.

When using GT methodology, the researcher is allowed to change the questioning, based upon the unfolding emerging themes derived from interviews. This was an appropriate methodology to study the process used by surrogate decision makers who had made the decision to withhold and withdraw life-sustaining measures in an intensive care environment. However, the use of language to discuss such a sensitive subject is an important component of designing such a study. Finding appropriately meaningful language for the study participant may be just as important as the information being sought.

Remembering the Patient

Surrogates had a need to discuss their loved one with the researcher so as to make that person more human or real and less the object of a research study. This introduction was important to many surrogates so as to remember who the deceased was and who the surrogate was in relationship to that person. These comments gave a tone or setting for the conversation that followed and helped the researcher to understand the connections of the surrogates their family and the loved one.

The idea of needing to remember the loved one is consistent with other researchers' findings. Work conducted by Hayes (2003) showed that surrogates moved between the past, present, and future to create a memory about the experience of ending life support for an incapacitated adult. Similarly, Jacob's work (1998) found that the bereaved look back over their lives with the deceased so as to create a new picture of their life without the loved one. In a study conducted by Danforth and Glass (2001), widows needed to have someone listen to the story of their loss so as to give meaning to

the death of the loved one. In work done by Horacek (1995), results showed that many surrogates continued to grieve the loss of a loved one like the loss of a "phantom limb," and that the relationship continued with the deceased in a different way. Finally, in work conducted by Tilden and colleagues (1999), surrogates decisions regarding life-sustaining measures were partially based on knowledge of the patient.

Before the death of their loved one in an intensive care environment, facilitating surrogates' remembrances of the patient may help surrogates to begin the process of grief before the actual death of their loved one. Simply asking the surrogate to tell the patient's story or to tell the health care team who that person was before the onset of illness could be of benefit to the surrogate. This may help the surrogate to establish what the person was like before the illness and what might be acceptable in terms of the quality of life that the patient may or may not enjoy after the hospitalization. The ability of the surrogate to remember can create a new picture of what life will be without the patient. These anticipatory actions may make decision-making easier for the surrogate.

Being in an intensive care environment is foreign to most surrogates. Helping the surrogate to recall his or her relationship with the patient could create some sense of safety and structure by allowing the surrogate to retreat to the known. In effect, this may help surrogates to balance the unknown and sometimes intimidating health care world against the patient's and surrogate's wishes for continued aggressive care.

IMPLICATIONS

Education

The surrogates in this study repeatedly gave examples of the need for more education among health care providers concerning end-of-life decision-making. Information gathering and understanding was at the center of much of the surrogates' work. Attempting to get information from the health care team and then discuss that information with family members left room for misunderstanding or confusion on the surrogates' part. Finding ways to communicate information in a more concise manner requires that health care providers undergo specific education related to dealing with surrogates and end-of-life care.

Programs such as Educating Physicians in End of Life Care (EPEC) and End of Life Nursing Education Consortium (ELNEC) (End of Life Nurse Education Consortium Trainer's Guide, 2001) have helped to improve health care professionals' language and techniques for communicating to surrogates. Both ELNEC and EPEC recommend that nurses and physicians should be given the opportunity to learn how to care for the dying and thus support the families of the terminally ill. However, programs such as ELNEC and EPEC are voluntary programs and as such allow valuable information to go undiscovered by nurses and physicians in training. The issue of how to communicate news that could eventually lead to the withholding and withdrawing of life-sustaining measures should be mandatory in undergraduate and graduate curricula for both nurses and physicians.

The need for better communication skills is not a particularly unique observation. Through essays, Quill (2000) and Cohen-Almagor (2000) have been attempting to educate the health care community as to how bad news is communicated to patients and their families at the end of life. Writings by Lynn and colleagues (Lynn, 2001; Lynn, Schuster, & Kabcenell, 2001) have tried to educate clinicians how to communicate with patients and families in a variety of ways. These researchers have compiled a text regarding the care of the dying and devote significant thoughts on how to communicate with terminally ill patients and the families most often called to be the surrogate decision-makers.

Zoloth-Dorfman (1998) wrote an admonition to physicians to be particular in discussing details with the dying patient, as this interaction remains one of the most intimate encounters between providers and recipients of health care. Families and surrogates should not be thought of as separate from the patient; therefore, the same level of particular detail should be enjoyed by the all parties involved in the decision-making. Even in the face of literature asking health care providers to develop communication skills regarding patients' end of life, this topic remains unresolved. Surrogates in this study expressed a desire for clinicians, particularly physicians, to learn to communicate in a compassionate way to advance decisions in intensive care environments.

According to the surrogates in this study, compassionate delivery of difficult information facilitates the trusting relationship between the surrogate and the physician. In many surrogates' opinions, this trusting relationship is necessary for surrogates to make competent decisions. Learning the artful skill of communicating may reduce the

burden on the surrogate and physician, while assuring that through surrogates, patients' wishes are being honored and onerous treatments are not endured when not wanted.

Practice

This study found that nurses can and do assist surrogates in making decisions regarding withholding and withdrawing of life sustaining measures. This study found that nurses aid surrogates in intensive care waiting environments through helping surrogates and families understand complicated medical information. Work done by Tilden and colleagues (2001) found that clear communication by the health care team helped families in making the decision to forgo life-extending treatment. Jeffers' (1998) work cautioned nurses to assure that communication with surrogates is meaningful and understandable. Jacob's (1998) research found that nurses can best help surrogates through education and facilitation of goals for the incompetent patient. These researchers' findings, in addition to this study, suggest that nursing practice can assist surrogates in making decisions regarding the withholding and withdrawing of life sustaining measures.

The findings suggest that there is an opportunity to improve nursing practice. Two surrogates spoke about the need to have someone other than the physician speak to the surrogate and family about withholding and withdrawing of life-sustaining measures. These surrogates were confused by the conflicting physicians' opinions, the use of technical language, and the lack of an amicable relationship with the physicians. These surrogates advised the researcher that a nurse should fill this role and make certain that the surrogate and family clearly understood the futile nature of the care and the options related to continued treatment versus discontinuation of treatment.

Perhaps the greatest potential for practice change is in the inclusion of multidisciplinary discussions with surrogates regarding the terminal nature of the patient's condition. Many of the surrogates were distressed about the words and tone of voice that were used to communicate issues around the futility of the patient's condition. Some surrogates were angered by physicians who were felt to be insensitive or uncaring. Some surrogates expressed that they did not have a decision to make other than the one that they did make, and they expressed feelings that physicians gave them no other choice than to withhold and withdraw life-sustaining measures.

Conversely, most participants were complimentary of nurses who were felt to translate complicated medical terminology into language that decision makers could use in making their decisions. Nurses were almost always seen as supportive and understanding of the needs of the surrogates. Helping surrogates to evaluate the patient's condition and understand the complicated technology is within the parameters of nursing practice. Therefore, it behooves surrogates and health care team members connected with decision making to include as many parties as possible, particularly nurses who care for the patient and surrogate.

Physicians who include nurses in discussions related to withholding and withdrawing of life-sustaining measures provide surrogates the best from both professions. Physicians need to communicate diagnoses and prognoses regarding the patient, and nurses need to support surrogates in the long hours in the intensive care environment. This is not to say that physicians are not supportive. On the contrary, there are many physicians who can and do provide supportive information and contact with

surrogates. However, many physicians are not present when surrogates make visits to the patient's bedside. Nurses are available to help surrogates wrestling with decisions to withhold and withdraw life-sustaining measures. Surrogates will question nurses regarding the prognosis and treatment plan for the patient, and a team approach to dealing with surrogates will afford surrogates and patients the best possible decision regarding life-sustaining measures.

Understandably, inclusion of physicians, nurses, and other health care team members in every discussion with surrogates can place a great burden on the health care team members in terms of time and resources. Few full-time practicing physicians and nurses have an hour or more to discuss intricate details of aggressive intensive care. However, health care teams can validate surrogates' understandings during each encounter with the surrogates and their families, regardless of how much or little time is spent with the surrogate. This more accurately assures that informed consent and informed decision-making is taking place on behalf of the incompetent patient. Health care teams who fail to act in a way that assures informed consent is taking place are merely obtaining family agreement or assent to therapies and treatments that may not be wanted (Limerick, 2002). Clear and concise communication assists surrogates to move into this part of the decision-making process.

The study results suggest that the health care teams find ways to include as many of the family members as possible to participate in discussions related to continued aggressive care for an incompetent patient. This avoids duplication of effort on the part of the health care team as the person conveying information to the surrogate is less likely to

need to communicate with family members more than necessary. Surrogates may also be assisted in asking questions and ascertaining understanding of the patient's critical nature if more than one family member is present at the time futile care is discussed.

Physicians should be clear and unafraid to state their best medical opinion, and there should only be informed and educated predictions of the time a patient has left to live. However, waiting until the last possible moment to inform surrogates of the terminal or irreversible nature of a patient's condition can harm all parties involved. Surrogates are unable to make informed decisions regarding care for their loved one and may make other choices if not given a full range of information as the physicians, nurses, and other health care professionals come to these conclusions.

Physicians such as Quill (2000) and Lynn (2001) have been attempting to prepare physicians for this task. Programs such as EPEC and ELNEC (End of Life Nurse Education Consortium Trainer's Guide, 2001) have helped to educate health care professionals for the task of preparing surrogates for end-of-life decisions. While this is certainly an educational issue, the idea is that language used in the practice setting is critically important to the surrogate's ability to understand the complexities of the terminally ill. However, there is vast room for improvement and real practice changes regarding communication, specifically word choice or language as outlined in programs such as ELNEC and EPEC, must be implemented.

This has implications for all health care providers' practice in intensive care in that a language that is suitable to communicate these issues to surrogates must be found and used consistently. Helping surrogates with language that is personally and

connotatively meaningful will assure a greater understanding regarding the potential quality of life for the patient. Finding what is meaningful for surrogates, patient, and family will guide the health care team in discussing the patient's quality of life. Health care team members benefit by choosing to use language that has meaning for the decision maker (Cohen-Almagor, 2000).

For instance, the surrogate may relate that he or she wants the terminally ill family member to be able to return home to enjoy life in such ways as playing with grandchildren and working in the garden. If this is not possible, based upon the medical outcome, then health care providers have an obligation to communicate this limitation. In this way, the surrogate has a better understanding of what is and is not possible in terms of the patient's recovery. This study shows the need for health care team members to facilitate a surrogate's decision making by discussing complicated information in very clear and concise language early in the patient's terminal state.

Finally, the environment in intensive care areas could be modified to allow for surrogates to make decisions regarding the withholding and withdrawing of life-sustaining measures for a loved one. Given that most surrogates are surrounded by family and friends during this crucial time period, health care teams can facilitate surrogates' decision making by suggesting or encouraging surrogates to take a few moments at this critical juncture and be clear about their decisions. Arranging for a space to reflect quietly may be beneficial to surrogates as they struggle with this most important point in the process of deciding treatment options for an incompetent patient.

Research

Many of the surrogates in this study recalled the importance of communication skills and information. Formal education of nurses and physicians in the proper ways to communicate difficult information would lend itself to an intervention study and testing of this portion of the theory. A group of nurses and physicians using newly developed scripts or prompts to assist them in discussing withholding and withdrawing of life-sustaining measures could easily be compared to a group of nurses and physicians who have not had the assistance of this material.

While this type of communication and facilitation role for nurses was proposed in the Study to Understand Prognoses and Preference for Outcomes and Risks of Treatments (SUPPORT) (Murphy et al., 2000; Lynn et al., 2000; Connors et al., 1995; Hiltunen et al., 1999), no further research has been undertaken duplicating this effort in the current climate of health care. This may afford those in health care an opportunity to conduct this type of research and determine if surrogate decision makers are assisted, particularly by nurses, in decisions for incompetent patients in intensive care environments. Additionally, comparisons could be made between groups who did and did not have the assistance of the facilitation skills of nurses in intensive care environments.

The SUPPORT study (SUPPORT Principle Investigators, 1995) has been criticized for not having had an effect in surrogates' decisions concerning life support for patients in intensive care (Lynn et al., 2000). However, the dated nature of the study in the presence of the progress that had been made in end-of-life and hospice discussions may afford an opportunity to repeat the study (Lynn et al., 2000; Lynn & Adamson,

2003). Nurses with specific expertise in working with these types of difficult conversations can facilitate discussions regarding withholding and withdrawing of life-sustaining measures. An intervention study using nurses who are specifically trained in facilitating surrogate decision-making could determine the impact of nurses upon surrogate decision-making. These results could then be compared to the SUPPORT study for further indications of the success or failure of this type of intervention.

Many of the surrogates desired information on a regular schedule in order to make their decision to withhold and withdraw life-sustaining measures from a loved one in an intensive care environment. Did a perceived lack of information affect the timing and the manner in which surrogates made decisions? Would scheduled information time with physicians and nurses caring for the surrogate's love one facilitate the decision-making process in terms of some overt measure such as length of stay? Would facilitated information gathering reduce such things as hours on a ventilator, number of vasopressive medication doses, antibiotics, and chemotherapy (when compared to a control group)? This study gives direction for further research to examine some of the above-mentioned questions so as to better understand the surrogate's process in making the decision to withhold and withdraw life-sustaining measures from a loved one in an intensive care environment.

Even though the surrogates in this study were recruited through a Catholic managed health care system, there was no evidence to support that there was an influence of the teachings of the Catholic Church upon the surrogates' decisions. Additionally, since the time of this study, Pope John Paul II issued an Allocution (H.H. John Paul II,

2004) reaffirming the presumption in favor of artificial hydration and nutrition for those in a persistent vegetative state (PVS). This Allocution has been the source of some discussion in the American Catholic Church, and the influence of the Allocution should be a factor for future studies in Catholic institutions to determine if this Papal Allocution makes a difference in the way in which withholding and withdrawing of life-sustaining measures is enacted.

Analysis of the surrogates' stories revealed no influence of the Catholic Churches teachings upon surrogates' decision making. However, only one of the surrogates in this study was Catholic, and two of the patients were identified as Catholic. A repeated study with Catholic surrogates should be investigated to ascertain if indeed the Allocution has changed the way in which the faithful make decisions regarding the end of life, especially for those in PVS. Interviewing only Catholic surrogates in a Catholic hospital setting may reveal significantly different results regarding the influence of the Ethical and Religious Directives for Catholic Health Care Services (United States Conference of Catholic Bishops, 2001), particularly in view of the Papal Allocution issued by Pope John Paul II on March 20, 2004. As an example, do more patients endure unwanted artificial hydration and nutrition now when compared with those patients who received this type of treatment before the Allocution?

Furthermore, research should be conducted in secular institutions to determine if the theory presented in this study remains the same as it did in this study. A thorough testing of the grounded theory would need to include non-religiously managed institutions to ascertain if the decision-making process is differently influenced by

religiously managed health care systems. For instance, do surrogates have a sense of more support in a religiously managed health care system than in a secular institution? Do patients endure more unwanted treatment in one type of institution over the other? Answering questions regarding the amount of influence of the teachings of the Catholic Church may provide direction for other religiously managed health care systems that have similar teachings.

The surrogates in this study were mostly Caucasian, mostly educated, mostly Christian, and mostly middle to upper socioeconomic class. There is a need to conduct further research particularly in non-Caucasian groups. Other studies with related areas in end-of-life care are also not representative of minorities and underserved populations. The decisions to withhold and withdraw life-sustaining measures may be very different among minorities and could be the focus for a repeat of this study among different types of participants.

As part of the exclusion criteria for this study, decision makers for pediatric and trauma patients were eliminated from the potential pool of surrogates. As the surrogates who took part in this study were all adults who made decisions for adult patients, there is a need to investigate similarities and differences between the group represented by this study and surrogates who make decisions for other groups such as children. Additionally, surrogates who make decisions for patients who have died as a result of sudden events, such as may be seen with cardiac failure or motor vehicle accidents, may yield very different results and theory. The decision to exclude children and trauma patients from

this study is not regrettable. However, there is a need to investigate this phenomenon in these excluded groups.

CONCLUSION

This study was designed to understand the process surrogates used to make the decision to withhold and withdraw life-sustaining measures from a loved one in a Catholic intensive care environment. Thematic analysis of the surrogates' interviews revealed nine themes: (1) rallying family support, (2) evaluating the patient's condition against the surrogate's understanding, (3) viewing the potential quality of life for the patient, (4) getting information from the health care team (chasing doctors) , (5) expressions of the surrogate's relationship with the health care team, (6) the health care team confirms the potential medical outcome, (7) arriving at a new belief, 8) getting alone to make the decision, and (9) communicating the decision to withhold and withdraw. The analysis of the themes was used to develop a model and a grounded theory to explain the phenomenon of surrogates who made the decision to withhold and withdraw life-sustaining measures for an incompetent patient in the intensive care environment. The grounded theory will need to be tested and may be useful for nurses and other members of the health care team wanting to support surrogates as they make decisions for an incompetent patient in an intensive care environment.

The results of this study suggest that the nursing profession is in a unique position to foster decision making among surrogates in an intensive care environment. Effective communication among health care team members and between surrogates and health care team members is the best tool to assist surrogates in their decision-making process. The

use of clear, consistent, and connotatively meaningful language to explain the patient's condition assisted in the surrogate's understanding. Surrogates repeatedly expressed the desire for the health care team members to provide consistent communication and information about their loved one. Surrogates needed to know that the patient had received every chance for life-sustaining measures to be effective. When treatment regimens are no longer effective, surrogates needed health care team members to communicate this reality.

For those surrogates with the clearest sense of this information, decisions regarding withholding and withdrawing of life-sustaining measures were of the shortest duration and caused surrogates the least amount of doubt. Feelings of disbelief and uncertainty often plagued the surrogates in their decision making. Surrogates needed to have a clear understanding of the patient's potential quality of life and the potential medical outcome before this uncertainty and disbelief could be assuaged. The comfort of having family members present during the decision-making process often helped to reduce the surrogates' anxiety and allowed surrogates to obtain others' opinions regarding this crucial decision.

Surrogates did not always evaluate the patient's condition in terms of the burden of treatment. While this measure was most certainly the most prominent of the factors affecting the surrogate's decisions, the findings of this study would suggest that health care teams should investigate other measures of the patient's experience such as preconceived ideas about limiting treatment and if a plan was ever devised between the surrogate and the patient.

Allowing surrogates the time to understand complicated language and create a meaning from that understanding will foster independent and informed decisions by surrogates for incompetent patients. Given the intense nature and sensitivity necessary to facilitate fully end-of-life decision making, nurses can and often do develop caring relationships with surrogates and families. As nurses spend proportionately more time at the bedside than do physicians, nurses are in the most advantageous position to study this human phenomenon.

APPENDICES

APPENDIX A
LETTER OF SUPPORT FROM SETON HEALTH CARE NETWORK

SETON

1201 WEST 38TH STREET
AUSTIN, TEXAS 78705-1056
(512) 324-4000
www.seton.net

May 25, 2004

Michael Limerick, MSN, RN
University of Texas at Austin
School of Nursing
1700 Red River
Austin, Texas 78701

Re: Letter of support for research study entitled, "Withholding and Withdrawing of Life Sustaining Measures in a Roman Catholic Intensive Care Environment: Using Grounded Theory to Discern the Decision Making Process of Surrogate Decision-makers"

Dear Michael,

Your research study sounds very worthwhile and will provide insight into decisions made about life support for patients who are hospitalized in one of the Seton HealthCare Network facilities. I am particularly pleased that you are personally conducting this study. My experience with you and your work is that you take great care and use much compassion when you provide nursing care to those with terminal conditions. I know that you will continue to do so with surrogates who you enroll in your study.

On behalf of the Seton HealthCare Network Clinical Research Steering Committee, I support you in obtaining information such as names and addresses of surrogates who meet the criteria for your study.

Sincerely,

Carol Bales, RN

Carol A. Bales, RN, MSN, CCRP, AOCN
Chair, Seton HealthCare Network
Clinical Research Steering Committee

BRACKENRIDGE HOSPITAL
A member of the SETON Healthcare Network

Carol A. Bales
RN, MSN, AOCN, CCRP
DIRECTOR

OFFICE: (512) 324-7991 EXT 1
FAX: (512) 324-7792
PAGER: (512) 612-2051
INTERNAL EXT: 77322
E-MAIL: cbales@seton.org

CLINICAL RESEARCH
601 EAST 15TH STREET-RM L304A
AUSTIN, TEXAS 78701

ASCENSION HEALTH

APPENDIX B
LETTER OF SUPPORT FROM HOSPICE AUSTIN

HOSPICE AUSTIN™

Main Office:
4107 Spicewood Springs Rd
Austin, TX 78759
(512) 342-4700 • Fax (512) 795-9053
info@HospiceAustin.org
www.HospiceAustin.org

Inpatient Facility:
Hospice Austin's Christopher House
2820 E Martin Luther King Boulevard
Austin, TX 78702
(512) 322-0747
Fax (512) 477-7970

April 8, 2004

Michael Limerick, MSN, RN
University of Texas at Austin
School of Nursing, D0100
1700 Red River
Austin, Texas 78701

Dear Mr. Limerick,

I am pleased to write this letter of support for your doctoral research involving surrogate decision makers who have made the decision to withhold and withdraw life-sustaining measures in a Roman Catholic intensive care environment.

I understand that the research will involve contact with people who have made the decision to withdraw and withhold life-sustaining measures while a loved one was in one of the Seton system intensive care environments. After obtaining the names of persons who had life-sustaining measures withheld or withdrawn, you will contact their surrogates via a letter. This letter from you to the surrogates will invite them to participate in the study, and they may choose to do so or not.

Should any of the study participants have need of qualified grief counseling, they may be referred to our grief support groups at no cost. Their participation in the study or in the support groups will, in no way, affect any future care that may be received from Hospice Austin.

I understand that you have completed the HIPPA requirements as designated by federal law and that you will adhere to the utmost confidential handling of patient/family information.

Should your dissertation committee members need further information regarding this service, please ask them to contact me or Caroline Huffman, Director of Family Services. We may be reached through our main switchboard number, (512) 342-4700.

Sincerely,

Marjorie Mulanax

Marjorie Mulanax
Executive Director

a Partner Agency of
UNITED WAY
CAPITAL AREA

APPENDIX C
RECRUITMENT LETTER

APPENDIX C
COVER LETTER
Part 1, from Seton Health Care Network

Date

Name
Address
City, State zip

Dear Family Decision Maker,

In order to protect your privacy, we are sending you the enclosed letter from one of our partners at the University of Texas at Austin. Your information has **not** been shared with the University in any way. You have been sent this letter as someone who recently had to make a difficult decision for someone who was in one of our intensive care units.

We encourage you to take part in this study as one way in which you can help us to serve others like you who have had to make difficult decisions. Mr. Limerick is the former head of our Palliative Care program and serves on our ethics committee. We feel that he is qualified to help us understand your situation and he will treat you utmost confidentiality. The individual information you share with Mr. Limerick will not be shared with Seton Healthcare Network. Only group results will be shared with Seton.

If you should have any questions regarding this letter, please contact one of the nursing managers listed below.

Sincerely,

Francis Simpson, RN, MSN
Clinical Manager
Intensive Care
Seton Medical Center
324-1000

Betty Thornell, RN, MSN
Clinical Manager
Intensive Care
Brackenridge Hospital
324-6000

Enclosure: Letter from Mr. Limerick

APPENDIX C
COVER LETTER
Part 2, from the Researcher

End of Life Decision-Making in ICU

This letter is being sent to you because you have been identified by Seton as someone who made a very difficult decision for a loved one in the intensive care. In order to protect your privacy, Seton has not shared your contact information with me.

My name is Michael Limerick and I am a registered nurse who is completing a PhD in nursing. I am also a part-time faculty member at the University of Texas at Austin. My research is looking at the decision-making process that you might have used during that time you made a decision for a loved one and I am conducting a study about this. I understand that this may be a hard time for you and I do not wish to impose or cause you discomfort in this period following your time in the hospital.

I am writing to find out if you are willing to take part in this study. This will help us learn about decision-making and how people in health care can help others like you in the future. I invite you to take part in this study as one of about 20 people who have recently faced a similar experience. As a thank you for participating in the study, I will give you $40.00 cash at the time of the interview.

If you decide to take part in this study, you and I will arrange a convenient time and place to interview you. This will take about 1 hour and will be tape recorded. I will ask you questions about the process you used to make the decision about life support for your loved one.

All information about you will be held confidential by using a made up name that you may choose. To tell your story I may need to quote you in my dissertation; But your information will be protected by using your fictitious name. Your name and the names of others will not be printed on any report. All tape recordings will be kept under double lock and key and will be erased at the end of the study. I may share information with Seton but only the results as a group of people -not about any individual person.

If you are interested in taking part in this study, please contact me in one of the following three ways:

1. You may call me at (512) 232-4702 and leave a private message. When you call, please tell me your name, phone number, and the best time to contact you. Leaving your name and number gives me permission to contact you.

OR

2. You may send an e mail at **mlimerick@mail.nur.utexas.edu**. Please include your name, phone number, and the best time to contact you. E-mailing me gives me permission to contact you.

OR

3. You can mail the enclosed card in the self addressed stamped envelope which will come to my private post office box number. You will need to write your name, a phone number, and the best time to contact you on the card.

I will contact you at the time you indicate to discuss the study and answer any questions you may have. When we speak on the telephone, I will be happy to talk about the study with you in more detail. You can decide if you wish to take part in the study when we talk by phone. If you do decide to take part in the study, we can set up a time and place where we can tape record our conversation.

If you agree, I may want to contact you after results of the study are available. If you wish, I would ask that you give me your opinion about the study findings.

Your decision to take part can be changed; you can stop being in this study at any time. If you decide not to take part in this study, I thank you for your willingness to read this letter.

I know this is a difficult time for you right now, but I hope we have the chance to work together to help others like yourself. I look forward to hearing from you.

Sincerely,

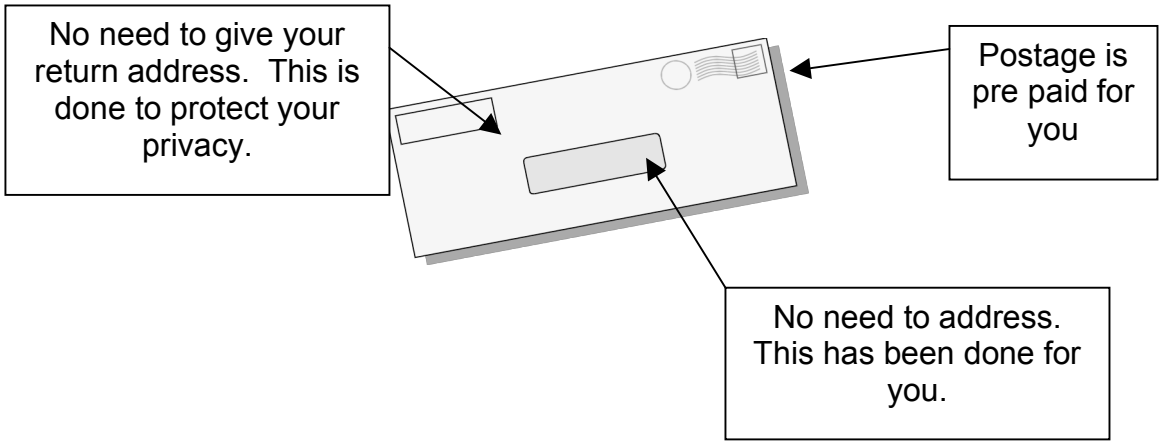
Michael Limerick, RN
Doctoral Student at the University of Texas at Austin
School of Nursing

enclosures

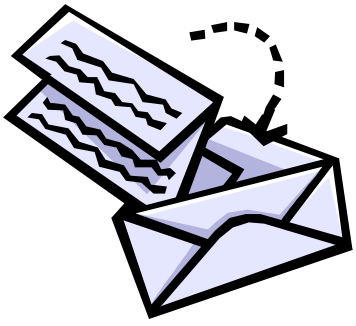
Instructions for returning reply card:

Sending your contact information is as simple as filling out the enclosed card and mailing it in the addressed stamped envelope to:

Michael Limerick
P. O. Box 10073
Austin, Texas 78766



Fill out the card and then



place the card in the envelope

Reply Card:

Thank you for your interest in the End of Life Decision-making in ICU study. We appreciate your willingness to take part in this important work. Please fill in the following blanks with your name, preferred phone number where you may be reached, and the preferred time you wish to be contacted. Thank you.

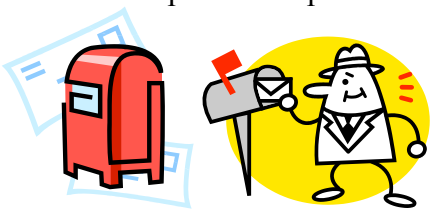
Your name: _____

Preferred phone number: _____

Preferred time of day to contact you: _____

By completing this information, you agree to allow the researcher to contact you as designated above.

Place this card in the self-addressed stamped envelope that was provided to you and mail.



APPENDIX D
INTERVIEW GUIDE

The following format is not intended to indicate the exact order of each interview. The researcher will use an approximation of the following words prior to beginning the actual recorded interview.

All interviews will be individualized as per the needs and understanding of the study participant; however key elements will be queried. These will include the environment, the surrogate's perception about the experience, the process used to withhold and withdraw life sustaining measures, and the Catholic Ethical and Religious Directives. An example of the type of individualization needed to obtain data is given in question 5.

Self-disclosure will be given at the beginning of the interview such as the researcher's extensive clinical experiences in dealing with those who faced the decision to withhold and withdraw life-sustaining measures.

I understand that this may be a very hard time for you. I really appreciate your willingness to speak with me.

As you know, I am working on a research project that will help others in health care understand how surrogates make the decision to withhold or withdraw life support in a Catholic intensive care. I hope to better understand how you and others who have had a similar experience made the decision to withhold or withdraw life sustaining measures. This information will help others like you who will one day have to make a decision similar to yours. Do you feel like going on? (If yes, continue. If no, ask to reschedule the time and place that might be more to the study participant's liking.)

I would like to speak with you for about an hour and tape record our conversation. I would like to ask questions about your loved one, about you, about the hospital and the staff who took care of (state the patient's name). I would also like to ask about the Catholic teachings that govern the hospital where (state the patient's name) was before he/she died. Everything you say to me will be strictly confidential and no information will be shared about your specific experience with the hospital, doctors, or nurses.

If at any point during the interview you become uncomfortable, just let me know and we can stop the interview and reschedule to a time that better suits your needs. You may withdraw from the study at any time and for any reason. Would you like to go on? (If yes, continue. If no, ask to reschedule the time and place that might be more to the study participant's liking. If the participant decides not to continue in the study, thank them for their time and leave.)

Before we go on, do you have any questions? (Answer all questions)

Would you like to participate in the study? (If yes, obtain informed consent. If the participant decides not to continue in the study, thank them for their time and leave.)

About the precipitating event-**the grand tour question**:

1. Can you tell me something about what brought your loved one to the hospital for the last time?

About the surrogate's perceptions about the experience:

2. What part of the process was especially difficult for you?

About the environment:

3. What went right while you were in the intensive care?

4. What went wrong while you were in the intensive care?

5. What would you wish the doctors and nurses would have done differently?

About the process:

6. Some people believe that there is a process to follow when making the decision to withhold and withdraw life-sustaining measures. Was this so for you?

Some alternate forms using substitute language might be:

a. Can you list the steps you used to decide to stop all the medicines and machines?

(Readability: Flesch Reading Ease = 84.8 and Flesch-Kincaid Grade Level = 5.4)

b. If you could write a book about what happened, what would the chapter titles be?

(Readability: Flesch Reading Ease = 84.4 and Flesch-Kincaid Grade Level = 5.2)

c. If you were sending a recipe about this to a friend who has to do the same thing that you did, what would you put on the card?

(Readability: Flesch Reading Ease = 84.7 and Flesch-Kincaid Grade Level = 8.3)

Other forms of this question might be more direct. The study participant's responses will guide the researcher to use other probes such as:

d) Tell me how you made the decision to withhold and withdraw life sustaining measures from your (state relationship to the interviewee e.g. husband, wife, daughter, etc.)? or:

e) Tell me about the decision to withhold and withdraw life sustaining measures from your (state relationship to the interviewee e.g. husband, wife, daughter, etc.).

About the Catholic Ethical and Religious Directives:

7. The hospital where you and your family made these decisions is a Catholic hospital. Did you choose to come to a Catholic hospital?

8. If you had a choice, would you choose to go to a Catholic hospital again?

9. Do you think that the Catholic beliefs had any influence on your decision to withhold and withdraw life-sustaining measures?

Other possible questions:

10. I was wondering if you talked to other people-family, friends, neighbors or any health care professionals.

11. Did you get opinions from anyone else? Who?

[1] (Overall Readability statistics-exclusive of alternate forms of question 6:
Flesch Reading Ease = 67.6 and Flesch-Kincaid Grade Level = 6.7)

APPENDIX E
DEMOGRAPHIC FORM

Instructions: Please fill in the black or check the appropriate space for the following questions. Select only one answer per question. You may choose to omit any question.

ABOUT YOU:

1. **Your** relationship to the person who was in intensive care:

_____ wife
_____ husband
_____ partner
_____ mother
_____ father
_____ brother
_____ sister
_____ grandmother
_____ grandfather
_____ cousin
_____ friend
_____ other: _____

2. **Your** age _____

3. **Your** gender: _____ female _____ male

4. **Your** religious preference: _____ (even if none)

5. **Your** attendance at religious services**:**

_____ every day
_____ 2-3 times a week
_____ 1 time a week
_____ none or never
_____ special occasions only (such as holy days)
Other_____

6. **Your** highest level of education:

_____ grade school
_____ some high school
_____ graduated from high school
_____ some college
_____ college degree
_____ masters degree
_____ doctoral degree
_____ post doctoral degree

7. **Your** Ethnicity

_____ African-American
_____ Alaska Native
_____ American Indian
_____ Asian
_____ Native Hawaiian
_____ Pacific Islander
_____ White
Other_____

ABOUT YOUR FAMILY MEMBER:

8. **His/Her** age _____

9. **His/Her** gender: _____ female _____ male

10. **His/Her** religious preference: _____
(even if none or unknown)

11. **His/Her** attendance at religious services**:**

_____ every day
_____ 2-3 times a week
_____ 1 time a week
_____ none or never
_____ special occasions only (such as holy days)
_____ unknown
Other_____

12. **His/Her** highest level of education:

_____ unknown
_____ grade school
_____ some high school
_____ graduated from high school
_____ some college
_____ college degree
_____ masters degree
_____ doctoral degree
_____ post doctoral degree

13**. His/Her** Ethnicity

_____ African-American
_____ Alaska Native
_____ American Indian
_____ Asian
_____ Native Hawaiian
_____ Pacific Islander
_____ White
Other_____

APPENDIX F

IRB# _____

Informed Consent to Participate in Research

The University of Texas at Austin

You are being asked to participate in a research study. This form provides you with information about the study. The Researcher, Michael Limerick, will also describe this study to you and answer all of your questions. Please read the information below and ask questions about anything you don't understand before deciding whether or not to take part. Your participation is entirely voluntary and you can refuse to participate without penalty or loss of benefits to which you are otherwise entitled.

Title of Research Study:

Surrogate decision-makers decisions to withhold and withdraw life sustaining measures in a Catholic intensive care environment: A grounded theory study

Principal Investigator(s)

Michael Limerick, MSN, RN
232-4702

Debbie Volker, PhD, RN
471-9088

Funding source:

Oncology Nursing Society Foundation

What is the purpose of this study?

The study will examine the process used by surrogate decision makers to make the decision to withhold and withdraw life sustaining measures in a Catholic intensive care environment. Approximately 20 subjects will be interviewed to examine this process and bring greater understanding to the health care provider in support of those who must make these decisions.

What will be done if you take part in this research study?

You will be asked to participate for at least one hour in a tape recorded interview. You will be asked about the experiences you had while your loved one was in the intensive care. This information will be compared to others who have had like or similar experiences to develop a theory of understanding about your experience. You will also be asked to complete a demographic form.

What are the possible discomforts and risks?

Many of the studies that are done by UT faculty/students do not involve physical risk, but rather the possibility of psychological and/or emotional risk from participation. You may experience some uncomfortable memories as a result of this study. You may refuse to answer any question or you may stop the interview at any time. You may withdraw from the study at any time. If you should require further assistance with the loss of your loved one, you may contact Hospice Austin (324-4700) to participate in their bereavement support groups FREE OF CHARGE.

If you wish to discuss the information above or any other risks you may experience, you may ask questions now or call the Principal Investigator listed on the front page of this form.

What are the possible benefits to you or to others?

There may be no direct benefit to you. It is our hope that your participation will help others who will face like or similar situations such as when you made the decision to withhold and withdraw life sustaining measures while your loved one was in the intensive care.

If you choose to take part in this study, will it cost you anything?

No, other than your time to complete the interview.

Will you receive compensation for your participation in this study?

No. You will however, receive a small stipend of $40.00 to compensate you for your time in taking part in this study.

What if you are injured because of the study?

No medical treatment will be provided or available in case of injury as a result of participation in this study. No treatment will be provided for research related injury and no payment can be provided in the event of a medical problem. If you should require further assistance with the loss of your loved one, you may contact Hospice Austin (324-4700) to participate in their bereavement support groups FREE OF CHARGE.

If you do not want to take part in this study, what other options are available to you?

Participation in this study is entirely voluntary. You are free to refuse to be in the study, and your refusal will not influence current or future relationships with The University of Texas at Austin or Seton Health Care Network

How can you withdraw from this research study and who should I call if I have questions?

You may withdraw from the study at any time by simply stating your wish to end your participation. We only ask that you contact Michael Limerick or one of the listed members of the team (see below).

If you wish to stop your participation in this research study for any reason, you should contact:

Michael Limerick, MSN, RN
232-4702

Debbie Volker, PhD, RN
471-9088

You are free to withdraw your consent and stop participation in this research study at any time without penalty or loss of benefits for which you may be entitled. Throughout the study, the researchers will notify you of new information that may become available and that might affect your decision to remain in the study.

In addition, if you have questions about your rights as a research participant, please contact Clarke A. Burnham, Ph.D., Chair, The University of Texas at Austin Institutional Review Board for the Protection of Human Subjects, 512/232-4383.

How will your privacy and the confidentiality of your research records be protected?

Authorized persons from The University of Texas at Austin and the Institutional Review Board have the legal right to review your research records and will protect the confidentiality of those records to the extent permitted by law. If the research project is sponsored then the sponsor also has the legal right to review your research records. Otherwise, your research records will not be released without your consent unless required by law or a court order.

If the results of this research are published or presented at scientific meetings, your identity will not be disclosed. As this study will involve the use of recorded information, you must know the following:

(a) The interviews or sessions will be audio taped;
(b) The cassettes will be coded so that no personally identifying information is visible on them;
(c) You may choose a fictitious name for yourself and your loved one. If you do not wish to do this, the researcher will choose names for you and your loved one.
(d) The cassettes will be kept in a locked file cabinet in the investigator's office;
(e) The cassettes will be heard or viewed only for research purposes by the investigator and his or her associates (a transcription service who are people who will listen to the tape and type your words into a document); and
(f) Those typed documents will be kept under lock and key.
(g) The cassettes may be reviewed for additional analyses at a later time and erased at the conclusion of the study. The transcripts will be retained for possible future analysis but will be kept under lock.

Will the researchers benefit from your participation in this study?

No, the researchers will not benefit. Publications may come from this data. However, no identifying information will be used in the publications.

Signatures:

As a representative of this study, I have explained the purpose, the procedures, the benefits, and the risks that are involved in this research study:

/Michael Limerick

Signature and printed name of person obtaining consent **Date**

You have been informed about this study's purpose, procedures, possible benefits and risks, and you have received a copy of this Form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time. You voluntarily agree to participate in this study. By signing this form, you are not waiving any of your legal rights.

Printed Name of Subject **Date**

Signature of Subject **Date**

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VITA

Michael Hyder Limerick was born and raised in Texas. After graduation from W. B. Ray High School in Corpus Christi, Texas, he entered San Antonio College in San Antonio, Texas. He received an associate degree in nursing in 1981. While working in multiple nursing roles including administration and care of the adult patient, he completed a Bachelor of Science degree with honors in 1988. His B.S. degree is from Southwest Texas State University in San Marcos, Texas and has an emphasis in Health Care Administration.

While working as a director of nursing for a large non-profit hospital system, he entered the University of Texas at Austin in 1992 and completed his Masters Degree in 1996 with an adult health clinical nurse specialist degree. His Masters Degree work focused in the care of the adult patient with HIV/AIDS.

In the fall of 1998, he entered the Doctoral program at the University of Texas at Austin. In the fall of 2003, he left his position as an advance practice nurse and Director of the Palliative Care Program for the Seton Health Care Network in Austin, Texas. He received the University Continuing Fellowship award for the academic year 2003-2004 and became a part-time faculty member for the University of Texas at Austin, School of Nursing. He continues to teach in the nursing program at the University.

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